



2011

Acts-Hf: Attention, Cognition and Self-Care in Heart Failure

Catherine M. Murks

Loyola University Chicago

Recommended Citation

Murks, Catherine M., "Acts-Hf: Attention, Cognition and Self-Care in Heart Failure" (2011). *Dissertations*. Paper 198.
http://ecommons.luc.edu/luc_diss/198

This Dissertation is brought to you for free and open access by the Theses and Dissertations at Loyola eCommons. It has been accepted for inclusion in Dissertations by an authorized administrator of Loyola eCommons. For more information, please contact ecommons@luc.edu.



This work is licensed under a [Creative Commons Attribution-Noncommercial-No Derivative Works 3.0 License](https://creativecommons.org/licenses/by-nc-nd/3.0/).
Copyright © 2011 Catherine M. Murks

LOYOLA UNIVERSITY OF CHICAGO
ACTS-HF: ATTENTION, COGNITION AND SELF-CARE
IN HEART FAILURE

A DISSERTATION SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL
IN CANDIDACY FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

PROGRAM IN NURSING

BY
CATHERINE M. MURKS

CHICAGO, ILLINOIS

AUGUST 2011

Copyright by Catherine M. Murks, 2011
All rights reserved

ACKNOWLEDGEMENTS

I would like to thank all of the people who have made this dissertation possible. First of all, I would like to thank Dr. Meg Gulanick, my committee chair, who listened to countless telephone calls, answered numerous emails and offered endless support and guidance throughout this long process. You were steadfast in your dedication to this project and to me, at times when even I, was not. I will never forget the support and assistance you have given me. To Dr. Sue Penckofer, whose knowledge of research design and statistics strengthened this project in more ways than one. To Dr. Savitri E. Fedson, who served as a physician champion, who provided endless, almost daily support and guidance and who is a cherished colleague. To Dr. Christopher Randolph, whose assistance with the art and science of neuropsychological assessment proved invaluable in this project. To Dr. Karen Egenes, who was a steadfast contributor to the design and implementation of this project. It is only through the work and support of this distinguished committee that this dissertation has come to fruition.

I would also like to thank Sigma Theta Tau, Alpha Beta Chapter, for their financial support of this project. The grant provided allowed me the funds to purchase study materials and provide parking vouchers for my study participants.

I also must thank all the other people at my study sites that have made this study possible. To Elinar Lowry, RN, PhD, who listened, encouraged and offered support and advice. To Barbara Valente-Bates, RN, MSN, Rosalind Davis Toombs, RN, MSN,

Molly Trappe, RN, BSN, Kathleen Furlong, RN, BSN, and Kim Runge, RN who supported the recruitment process, and just would not let me fail. To Drs. Allen Anderson, Maria Rosa Costanzo and Kirk Spencer, who graciously facilitated recruitment of patients attending their clinic areas. To all the clinic staff in the Cardiology Clinic at the University of Chicago Medical Center and the Midwest Heart Group for your hospitality and willingness to help.

I would also like to thank Shelly Steele, who provided the training in administration and scoring of the cognitive tests, and Chuanhong Liao for her statistical support.

I would also like to thank all my participants and their caregivers. Words can not express the debt of gratitude I hold for you.

Finally, I would like to thank my family. My husband John, who was there for me at the beginning of my formal education and supported my education from the start, I hold dear the sacrifices you have made for the sake of my higher learning. The patience you have displayed is more valuable to me than you can imagine. To my sons, Damian and David, and my granddaughter Gabrielle, I thank you for your love and understanding, your unending support and most of all, for the wonderful ability you have to provide me with timely distraction and humor. Without all of you, this entire process would have been almost unbearable.

To my parents, Clarence Glowski and Cecelia Glowski Tomczak

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	iii
LIST OF TABLES	ix
LIST OF FIGURES	xi
ABSTRACT	xii
CHAPTER ONE: DESCRIPTION OF THE PROBLEM	1
Introduction	1
Epidemiology of Heart Failure	2
Self-care in Heart Failure	5
Cognitive Impairment in Heart Failure	10
Significance/Research Question	17
CHAPTER TWO: REVIEW OF THE LITERATURE	19
Introduction	19
Cognition and Cognitive Impairment	19
Conceptual Framework	24
Self-care in Heart Failure	29
Living with Heart Failure	29
Self-care Techniques	31
Barriers and Aids in Performing Self-care	36
Interventions to Improve Self-care	46
Instrument Development	49
Cognitive Impairment in Heart Failure	54
Prevalence and Demographics	54
Measurement of Cognitive Function	57
Physiologic Variables	93
Outcomes and Behaviors	98
Cardiac Transplant Candidates	101
Nursing Investigations	104
Limitations of Current Research	107
CHAPTER THREE: METHODS	109
Introduction and Study Aims	109
Study Design and Rationale	110
Setting	110
Sample	112
Independent Review	113
Inclusion/Exclusion Criteria	113

Measurement	114
Power Analysis	117
Procedure	118
Analysis	123
 CHAPTER FOUR: RESULTS	 126
Study Aims	126
Analysis	126
Sample	127
Sample Characteristics	128
Descriptive Statistics for Cognitive Variables	131
Repeatable Battery for the Assessment of Neuropsychological Status	131
Anosognosia Questionnaire-Dementia	132
Controlled Oral Word Association	133
Reliability of Cognitive Variables	134
Cognitive Status	134
Heart Failure Anosognosia	136
Self-care in Heart Failure	138
Correlations Between Variables	140
Correlation of Cognitive Variables to Self-care Variables	142
Regression of Cognitive Variables Against SCHFI Scales	142
Tests of Assumptions of Multivariate Regression Analysis	148
Admission Days: Secondary Aims	150
Important Results of this Study	153
 CHAPTER FIVE: DISCUSSION	 155
Sample	155
Cognitive Measures	157
Repeatable Battery for the Assessment of Neuropsychological Status	157
Controlled Oral Word Association	161
Anosognosia Questionnaire-Dementia	163
Heart Failure Specific Anosognosia	166
Self-care in Heart Failure	167
Regression of Self-care Variables	171
The Effect of Minority	174
Admission Days: Secondary Aims	176
Study Limitations	177
Important Findings	178
Implications for Providers	178
Implications for Further Research	183
 APPENDIX A: STUDIES OF COGNITIVE IMPAIRMENT IN HEART FAILURE	 185

APPENDIX B: THE SELF-CARE IN HEART FAILURE INDEX	249
APPENDIX C: THE REPEATABLE BATTERY FOR THE ASSESSMENT OF NEUROPSYCHOLOGICAL STATUS	252
APPENDIX D: PSYCHOMETRIC PROPERTIES OF THE REPEATABLE BATTERY FOR THE ASSESSMENT OF NEUROPSYCHOLOGICAL STATUS	254
APPENDIX E: PATIENT AND CAREGIVER FORMS OF THE ANOSOGNOSIA QUESTIONNAIRE FOR DEMENTIA	268
APPENDIX F: LETTER OF COOPERATION FROM MIDWEST HEART SPECIALISTS	277
APPENDIX G: FINAL APPROVED CONSENT DOCUMENT	280
APPENDIX H: SCREENING/DEMOGRAPHIC FORM	287
APPENDIX I: RELIABILITY STATISTICS OF STUDY VARIABLES	289
APPENDIX J: DESCRIPTIVE STATISTICS OF THE REPEATABLE BATTERY FOR THE ASSESSMENT OF NEUROPSYCHOLOGICAL STATUS	292
APPENDIX K: DESCRIPTIVE STATISTICS OF THE ANOSOGNOSIA QUESTIONNAIRE-DEMENTIA	294
APPENDIX L: CORRELATIONS BETWEEN STUDY VARIABLES	297
APPENDIX M: PERMISSIONS	303
REFERENCE LIST	315
VITA	335

LIST OF TABLES

Table	Page
1. Definitions of Cognitive Domains	23
2. Reliability of Self-Care in Heart Failure Index	52
3. Factor Loadings From Confirmatory and Exploratory Factor Analysis	53
4. Differences Between Groups	53
5. Subscale and Total Intercorrelations	54
6. Cognitive Domains Noted to be Impaired in Studies and Where Cited	55
7. Cognitive Tests	60
8. Correlations of COWAT to Stroop Test by Brain Lesion Location	81
9. Psychometric Properties of the Controlled Oral Word Association Test	84
10. Psychometric Properties of the AQ-D	92
11. Sample Characteristics	128
12. Comparison of Site One Participants to Site Two Participants	130
13. Cognitive Status of Participants	135
14. Descriptive Statistics for Heart Failure Anosognosia	137
15. Self-Care in Heart Failure Index Scores	139
16. SCHFI Item Descriptive Statistics	140
17. Beta Weights for Total RBANS Against Self Confidence	143
18. Beta Weights for Immediate Memory Against Self Confidence Scores	144

Table	Page
19. Beta Weights for Total Model Against Self Confidence Scores	147
20. Beta Weights for Model Loneliness, Minority Race, Immediate Memory Against Self confidence	148
21. Comparisons Between Participants Admitted and not Admitted	151
22. Mann Whitney Ranks for AQ-D Divergent and Participant Scores	152

LIST OF FIGURES

Figure	Page
1. Conceptual Model of the Self-Care Process	25
2. Murks' Model of Self Management in Heart Failure	28
3. Revised Murks' Model of Self Management in Heart Failure	182

ABSTRACT

Patients with heart failure (HF) are required to participate in self-care activities. These activities include taking prescribed medications, monitoring for symptoms, intervening appropriately and evaluating the response to the treatment. Cognitive impairment occurs relatively frequently in this population. Few studies have attempted to describe the nature of the relationship between self-care and cognitive impairment in this population.

This study investigated the relationship between cognitive function and self-care ability in patients with HF. It also investigated the relationship between both self-care and cognitive function and subsequent hospital admission.

Participants were recruited from outpatient areas at two cardiology groups specializing in the management of patients with HF. Study variables were assessed at a single visit. Participants were contacted 90 days after study visit to ascertain admission.

The Self-care in Heart Failure Index, the Repeatable Battery for the Assessment of Neuropsychological Status, the Anosognosia Questionnaire-Dementia and the Controlled Oral Word Association, as well as a number of demographic variables were used.

SPSS version 19 was used to perform the statistical analysis. Spearman's correlations and hierarchical multiple regression was used to assess the relationship between variables.

The prevalence of cognitive impairment was relatively high in the study group. Similarly, the prevalence of inadequate self-care ability was also high in the study group. Cognitive measures were moderately correlated to each other, but not to the Self-care in Heart Failure Index subscales. Regression analysis demonstrated that only immediate memory predicted self confidence scores when adjusted for loneliness, and minority status.

This study failed to demonstrate the proposed relationships. Cognitive impairment is a common finding in patients with HF. Most participants endorsed poor self-care ability.

Nurses need to be attuned to evidence of cognitive dysfunction in patients with HF. For any patient demonstrating cognitive dysfunction, independent verification of self-reported symptoms or response to therapy should be obtained.

CHAPTER ONE

DESCRIPTION OF THE PROBLEM

Introduction

Heart failure (HF) is a chronic health problem affecting approximately five million individuals in the United States (National Heart, Lung and Blood Institute, 2006). Those individuals must participate in their own health care by taking many oral medications, monitoring symptoms on a daily basis and notifying health care providers when necessary. However, many individuals with HF may be unable to adhere to this complicated self-management regimen. Cognitive impairment (CI) is a recognized phenomenon in HF, and may limit an individual's ability to participate successfully in self-management. This chapter introduces the study at hand. The brief literature review describes the phenomena of self-management and CI in HF, including scientific findings related to the phenomena, and proposes relationships between them. This introductory chapter then provides support for the need for this study through the presentation of the following topics: epidemiology of heart failure, the burden of heart failure, self-care in heart failure and finally, cognitive impairment in heart failure. Subsequently, this chapter ends with a description of the research questions for this study, to examine the relationship between self-management, CI and outcomes in individuals with HF.

Epidemiology of Heart Failure

Cardiovascular disease in general is a growing public health problem and HF is no exception. According to the National Heart Lung and Blood Institute (2006), approximately five million Americans are affected with HF with an additional 500,000 new cases diagnosed each year. Prevalence increases with age, male gender and race with a prevalence for African American males over age 85 of 50.6 cases per 1,000 population, as opposed to Caucasian women age 45-74 with a prevalence of 8.2 cases per 1,000. All in all, a total of about 15.2 per 1,000 population new cases of HF are diagnosed each year. The economic burden of HF is also disproportionately high, as patients with HF visit the outpatient area an average of 3.4 times per year, at a total cost of thirteen billion dollars annually (O'Connell, 2000). Not only is outpatient care affected, but there is increased hospital utilization in HF as it accounted for 990,000 hospital discharges in 2007 (Roger, et al, 2011). Despite this heavy use of health care resources, individuals hospitalized with HF face a 10.4% thirty day mortality rate, a 22% one year mortality rate and a 42.3% five year mortality rate (Roger, et al., 2011).

Oddly enough, current trends would suggest that the burden of HF in the population will only increase. As healthcare providers learn more about HF and its treatment and discoveries in the areas of technology, medical therapy and device therapy are made, many more individuals are affected by HF. This can be illustrated in acute myocardial infarction. Advances in technology have meant that many more patients are surviving myocardial infarctions and other acute cardiac diseases, largely due to advances

in percutaneous coronary interventions and surgical procedures. Many of these patients will survive their initial event only to develop HF at a later time (National Heart Lung and Blood Institute, 1996). Improved survival has been demonstrated in patients with known HF with the utilization of angiotensin converting enzyme inhibitors (Garg & Yusuf, 1995), beta blockers (CIBIS Investigators and Committees, 1994; CIBIS II Investigators and Committees, 1999; MERIT-HF Study Group, 1999; Packer et al., 2001) and vasodilators (Cohn et al., 1986; Cohn et al., 1991). Finally, device therapies, such as implantable cardioverter defibrillators and bi-ventricular pacers, have provided similar survival benefits in patients with HF (Bristow et al., 2004; Cleland et al., 2005). As survival increases, so does the sheer number of individuals affected with heart failure. Lastly, the ever increasing percentage of the population over the age of 65 will lead to a similar increase in the prevalence of HF (National Heart Lung and Blood Institute, 1996). In 2000 O'Connell estimated that there will be approximately ten million individuals with the diagnosis of heart failure in 2007, doubling previous estimates. It can certainly be said that population trends together with the advances in the care of HF have led to dramatic increases in the number of individuals who have HF as a chronic illness.

Not only is the economic burden of HF high, but the personal burden also weighs heavily. Individuals with HF experience distressing symptoms, must adapt to limitations in their activity and must perform self-care behaviors. Not only is this burden felt by the individual affected by HF, but it is also felt by family members or other caregivers as well. Patients with HF have described many difficult symptoms, including shortness of

breath, swelling, chest pain, fatigue, loss of weight, loss of balance, difficulty sleeping, and difficulty with position changes. Patients also report problems with cognitive areas such as memory loss and difficulty concentrating (Bennet, Cordes, Westmoreland, Castro & Donnelly, 2000). In addition to the physical symptoms and cognitive challenges, patients with HF often describe inability to complete previously performed tasks (Bennett, Baker & Huster, 1998). Caregivers must then compensate for these difficulties by performing these tasks and functions, such as driving patients to appointments and tests (Bennett et al., 2000).

Not only do individuals with HF experience troublesome symptoms, but patients also endorse a range of emotional problems such as fear, anxiety, depression, social isolation and lack of interest in sex (Bennett et al., 2000). These types of changes were described in a qualitative study by Zambroski (2003). In this study, six women and five men were interviewed to describe the experience of living with heart failure. Participants drew an analogy to navigation in their description of living with HF and described three key themes: experiencing turbulence, navigating, and finding safe harbor. Turbulence was described as a lack of stability in physical, emotional or social aspects of their lives due to their disease. While physical turbulence involved mostly signs and symptoms of HF, such as dyspnea and fluid retention, emotional turbulence involved a myriad of emotional responses, such as feeling bored, depressed, frustrated, guilty and jealous. Participants also felt social turbulence and described it as the limitations that treatment for heart failure placed on their ability to enjoy a social life. These limitations, much like

the limitations noted in the Bennett et al. (1998) study, included decreased social activities, decreased level of activity, and effects of medications like diuretics.

Navigating was described as the process of managing HF, from determining position (assessment), charting the course (evaluating the current conditions and determining a plan of action), operating (self-management methods to deal with turbulence), or being piloted (allowing another to care for the individual with HF). Lastly, finding safe harbor, was described as a feeling of safety, stability and freedom from symptoms (Zambroski, 2003). Patients feel, it would seem, as passengers in the voyage of their disease, and vacillate from active to passive activities during their illness trajectory. Critical examination of this study and other studies such as these illustrates just how great the physical, emotional and social burden imposed by a diagnosis of HF is for patients and their caregivers.

Self-care in Heart Failure

In addition to the heavy burden placed upon patients by distressing symptoms, patients who suffer from HF must adhere to a complicated medical regimen consisting of drug therapy, symptom monitoring, and healthcare provider notification. According to the American Heart Association/American College of Cardiology joint consensus guidelines on the medical therapy of HF, four drugs are considered imperative in the treatment of HF: diuretics, angiotensin converting enzyme inhibitors, beta blockers, and digoxin (Hunt et al., 2005) dosed once or twice daily. Recently, attention has turned to hydralazine and nitrates given singularly or in combination form (Cohn et al., 1986; Cohn

et al., 1991), which are dosed three times daily. Still other medications, such as potassium supplements, antiarrhythmics or anticoagulants, may be added, further complicating the regimen. Finally, medications used to treat concomitant illnesses, such as atrial fibrillation, diabetes or chronic obstructive pulmonary disease, increase the complexity of the therapy.

In addition to the complex medical regimen, persons with HF experience significant changes in lifestyle. These individuals must modify their diet to avoid sodium, visit their professional care providers, monitor vital signs, body weight and symptoms and notify their medical team if their condition changes. Patients with HF are seen as active participants in their care, and by performing these behaviors may promote well being and avoid unnecessary hospitalizations. In many situations, early intervention may avoid costly admissions to the hospital, such as in the case of fluid overload. Patients who carefully monitor their weight and symptoms are able to recognize changes and notify their healthcare provider. Adjustments in medical therapy, such as increased diuretic dosing, may alleviate symptoms and reduce volume overload. Self-care behaviors and appropriate adjustments in medical therapy could decrease symptom burden, return the individual to relative health and improve quality of life.

Lastly, in order to effectively manage their disease, individuals with HF are expected to assimilate a large body of knowledge. According to the Heart Failure Society of America, patient education is a necessary ingredient for successful patient management programs (Adams et al., 2006). Patient education should be aimed at

providing patients and their caregivers with the necessary knowledge and tools to engage in self-management and should include basic information about HF, warning signs of decompensation, strategies to combat decompensation, medications utilized, diet recommendations, exercise and activity restrictions and recommendations for adherence and consequences of nonadherence (Adams et al., 2006).

Many nursing researchers have sought to describe the experience of self-care in individuals with HF. Other studies have examined self-care activities, as well as aids and obstacles in performing self-care. Patients with HF describe self-care activities either very specifically, such as taking prescribed medications, visiting the physician as advised, weighing one's self, and following a fluid restriction (Artinian, Magnan, Sloan & Lange, 2002), or more broadly, such as altering physical activity patterns, breathing assistance, medication management, using assistive devices, adhering to a low sodium diet, monitoring for signs and symptoms of heart failure, assisting with sleep, enlisting support from family members (Bennett et al., 2000), and positive self assurance (Artinian et al., 2002; Bennett et al., 2000).

In addition to describing the experience of living with HF, many nurse researchers have examined those things that may help or hinder the ability of an individual with HF in the performance of self-care. Not only do patients with HF describe troublesome symptoms, but they also expressed apprehension about drug therapy, lack of knowledge about their drug therapy, difficulty in interpreting symptoms of heart failure as opposed to side effects of medications, difficulty in determining when to consult a healthcare

provider about symptom changes (Rogers et al., 2002). Some patients described the symptoms of HF themselves as an impediment to self-care, in addition to difficulties with symptom recognition and medication adherence (Riegel & Carlson, 2002). Some patients have attempted to compensate for these hindrances by developing memory aids such as medication lists and schedules, utilizing assistive devices, engaging the support of others and making lists (Riegel & Carlson, 2002).

Finally, lack of knowledge about self-care in HF is also described by some patients as an impediment to self-care. In a study performed by Ni, Nauman, Burgess, Wise, Crispell and Hershberger (1999), knowledge deficits in the area of self-care were described. Despite the fact that a majority (71%) of participants indicated that they had been informed about HF self-care, most indicated that they knew some (48%) or little or nothing (38%) about their own care. This was borne out in the area of symptom recognition, as 37% did not recognize weight gain and 52% did not recognize nocturia as symptoms of worsening HF. Similarly, 20% of participants did not know daily sodium allowance and 25% of participants did not know they should abstain from alcohol. On the other hand, most participants (74%) indicated they took their medications as prescribed, while some (25%) indicated they took their medications most of the time. Alternatively, adherence to other behaviors, such as weight monitoring, was worse, with only 57% of participants reporting adherence to daily weight monitoring and only 38-40% of participants who reported that limiting dietary sodium was important actually limited sodium intake. Although this study speaks to the importance of patient education,

it would seem that the mere act of providing education to a patient does not ensure self-care behaviors will result. On the contrary, despite the fact that patients in this study were told about sodium restriction, a small minority actually restricted their sodium intake.

Although patient education does provide the knowledge necessary for patients to participate in self-care, it alone does not ensure successful self-management. According to Riegel, self-care is “an active cognitive process in which persons engage for the purpose of maintaining their health or managing an illness” (Rockwell & Riegel, 2001, p. 18). Self-care is composed of both self-maintenance and self-management activities. Whereas self-maintenance refers to behaviors aimed at living a healthy lifestyle, such as healthy eating, exercising, taking medications as prescribed and limiting risk factors for diseases (Rockwell & Riegel, 2001), self-management refers to the “decision making undertaken in response to signs and symptoms” (Riegel, Carlson & Glaser, 2000, p. 5). Riegel, et al. (2004) believe that self-management is an active process where previous experiences are used to reach decisions about current care needs. In keeping with this nomenclature, individuals with HF would be participating in self-maintenance by taking their diuretics and weighing themselves, and would be participating in self-management when they increase their dose of diuretics in response to weight gain or edema. According to Riegel, in order to be successful at self-management, it is necessary that the patient is attentive to symptoms, judge these symptoms to be relevant and make a decision about therapeutic behaviors. In other words, patients with HF must recognize

alterations in their symptoms, recall learned knowledge, recall previous interventions, decide upon a plan, implement the plan and finally, evaluate the plan. Subsequent decisions about self-care management will consider the results of this as well as other management strategies.

Cognitive Impairment in Heart Failure

As one can see, self-care in HF involves many activities. Persons with HF experience great burden in symptoms, resource utilization and alteration in lifestyle. Not only must patients now adhere to a complicated regimen of oral medications, they must also visit the physician frequently, monitor their symptoms, engage in decision making and act appropriately based on their observations. The self-care process includes simple activities of self-maintenance such as taking medications as prescribed and monitoring vital signs, to more sophisticated self-management activities which typically involve complex decision making processes. It would seem that patient education is requisite to successful self-management, but, as noted in previous studies, providing patient education does in no way ensure adequate self-management strategies will be implemented by any given patient. What explains this phenomenon? Why do patients who have been educated in HF self-care fail to notify caregivers about symptoms, take their medications as prescribed, or understand the function of their medications? While the simple answer to this question may be that patients simply do not wish to engage in self-care, this author believes the explanation is multifactorial, and at the least, includes deficits in cognitive domains of memory, attention, insight and executive function.

Cognitive impairment is a frequently observed phenomenon in HF. In fact, it has been found to appear in 26% (Zuccala, Onder, Pedone, Cocchi et al., 2001) to 77% (Putzke et al., 1997) of patients with HF. Many studies have been performed in an effort to explain, predict or correlate CI with other variables. These variables include physiological variables such as ejection fraction and blood pressure; laboratory values such as hemoglobin or serum sodium levels; outcomes, such as mortality, readmissions or disability; or medications. Still others have tried to explain the personal experience of living with HF and CI. Rogers et al. (2002) reported that participants complained of memory loss, which was particularly problematic during physician visits. It was at this time that patients could not remember what they intended to relay to the health care provider. In other studies, Bennett et al. (2000) and Europe and Tyni-Lenne (2004) reported patients and caregivers complained of memory loss and inability to concentrate. While it is indeed important to know if specific variables correlate with CI in HF, it seems equally important to understand the effect CI has on the individual and their ability to perform self-care. Do the impairments in memory or concentration affect the ability to learn or retain information? Does impairment in memory mean patients are less effective in self-care? Can patients with CI perform self-care successfully and stay out of the hospital? To be certain, these are all questions that require comprehensive study to answer.

In order to understand what CI is, one must first define the concept of cognition. Cognition, according to *The American Heritage Dictionary* is broadly defined as “the

mental process or faculty by which knowledge is acquired” (Morris, 1980, p. 259).

Riegel, et al. (2002) simply define cognition as “those mental activities associated with thinking, learning and memory” (p. 522). On the other hand, Roy and Andrews (1999) imply a specific human quality, defining cognition as “a broad term encompassing the human abilities to think, feel and act” (p. 320).

Although the nature of human thought can be more or less broadly defined as cognition, cognition is itself, composed of many distinct, yet interrelated functions, or domains of cognition. For example, memory, one such domain, is the ability to remember information and later use it for specific purposes (Lezak, Howieson & Loring, 2004). Two or more stored items of information may be linked together in the process of thinking or reasoning, and may include functions such as abstract reasoning, complex reasoning, concept formation, and problem solving (Lezak et al., 2004). Another cognitive domain, attention, refers to the organism’s ability to only receive information, while orientation is an “awareness of self in relation to one’s surroundings” (Lezak et al., 2004, p. 337). Recently, neuropsychologists have recognized the domain of insight, which is a type of self awareness (Lezak et al., 2004). In the common sense, insight is the ability to understand the “true nature of a situation” (Morris, 1980, p. 679). In the neuropsychological sense, insight typically involves an awareness of the presence of a psychiatric disorder, however the term anosognosia refers to insight specifically in relation an illness or disability (Kolb & Whishaw, 2003; Lezak et al., 2004). Finally, executive function is an integrated activity describing the ability of a person to adapt to

situations. Executive function forms the basis of socially responsible, adult behavior (Katz & Harman-Maeir, 1997; Lezak et al., 2004). Put simply, cognition can be described as a human process that includes a wide range of interrelated functions known as domains, which include memory, reasoning, thinking and problem solving, to name but a few. A more complete discussion of cognition and cognitive domains will be completed in the subsequent chapter.

While it is important to understand what cognition is, it is also important to understand the concept of CI. Cognitive impairment is decreased ability in the one or more domains of cognition, such as perception, memory, learning, attention, or executive function that may appear as a level of function lower than the individual had previously, as a level of function lower than group norms, or as a level of function lower than a normal control group. In the particular case of HF, the domains of cognition most frequently affected include memory (Almeida & Flicker, 2001; DeShields, McDonough, Mannen & Miller, 1996), attention (Almeida & Tamai, 2001; Bornstein, Starling, Myerowitz & Haas, 1995), complex reasoning (Putzke et al., 2000; Schall, Petrucci, Brozena, Cavarocchi & Jessup, 1989), recall (Incalzi, et al., 2003; Sauve & Bennett, 1999), learning (Callegari et al., 2002; Incalzi, et al., 2003) and various psychomotor areas (Bornstein et al., 1995; Putzke et al., 1997).

When considering the importance of self-care in HF, the prevalence and pattern of CI has important implications. Patients with HF and memory impairment may not remember the content of education, the proper dosages of their prescribed medications, or

perhaps most importantly, that symptoms were experienced or even what interventions to take in response to symptoms. Deficits in recall may limit an individual's ability to relay symptoms to healthcare providers in an accurate manner. Finally, self-management behaviors, such as flexible diuretic dosing depends on complex reasoning, another noted deficit area.

Although it is important to consider the cognitive domains known to be affected in HF, it is also important to understand those domains which have not been extensively studied. For example, executive function is a complex domain of cognition that has not been widely studied in this population. Similarly, the domain of insight has not been studied at all. Both of these higher order cognitive functions are tremendously important in the process of self-management. The self-management process depends upon the ability of the person to first and foremost perceive symptoms, and secondly to evaluate these symptoms, and thirdly to recognize that perceived symptoms require change in behavior. Additionally, the decision making process in self-management relies heavily on intact executive function as it depends upon the patient's ability to draw upon experience to determine which self-care behaviors will be implemented. Patients with anosognosia (poor self awareness) may not be able to perceive their symptoms, leading to errors in self-care and inefficient self-management. On the other hand, patients with impairment of executive function will have difficulty in developing a plan, implementing the activity and evaluating the results and altering the plan. Difficulties in these more complex cognitive activities have broad implications in self-management.

Despite the fact that CI is widely present in HF, there has been little reproducibility of results in studies examining physiological, demographic or outcome variables. Multiple studies have linked female gender to CI in HF (Zuccala, Onder, Pedone, Carosella et al., 2001; Zuccala et al., 2003; Zuccala, Marzetti et al., 2005), but, there is disagreement regarding the association of age and educational level with CI, with some (Sabatini, Barbisoni, Rozzini and Trabucchi, 2002 ; Zuccala, et al., 1997) making associations between increasing age and prevalence of CI in individuals with HF, while others (Riegel et al., 2002) making no association between these two variables. Likewise, when the role of educational level was considered, it was noted to be that decreasing educational level was associated with increased prevalence of CI by Zuccala, Marzetti, et al. (2005), but not by Riegel et al. (2002). Similar inconsistencies were found in physiologic variables such as ejection fraction (Sabatini et al., 2002; Sauve and Bennett, 2000), New York Heart Association Class (Gorkin et al., 1993; Incalzi, et al., 2003), and blood pressure, (Riegel et al., 2002; Sauve and Bennett, 2000). Each of these variables was inconsistently associated with cognitive impairment in patients with HF, and in many of the studies, statistically significant results bore no clinical significance. This lack of reproducibility is also noted in variables such as ejection fraction (EF), New York Heart Functional class (NYHA), and blood pressure. While a complete discussion of these variables is beyond the scope of this paper, the reader is referred to Appendix A, Studies of CI in HF, for further information.

While most research in this area focused on physiologic variables, a few studies examined the relationship between CI and various outcomes or behaviors. Zuccala et al. (2003) examined the relationship between CI and mortality in a hospitalized sample. Participants in this study with CI had a higher mortality rate than those without CI. While the results of this study seem compelling, it is important to remember that CI is associated with increased mortality in the general population (Kelman, Thomas & Kennedy, 1994; Stump, Callahan & Hendrie, 2001). Still other studies have examined the phenomenon of symptom delay in HF. Friedman (1997) found that the average duration of time before health care was sought was 12 hours after symptoms began. Evangelista, Dracup and Doering (2000) reported much longer delay times, with patients waiting an average of 2.93 days. Although cognitive status was not measured in either of these two studies, Hou et al. (2000) correlated impaired cognitive function to lower education and less reported dyspnea symptoms. What explains the lack of reported symptoms or the treatment seeking delay patients with HF are shown to exhibit? Perhaps individuals with HF lack the insight to recognize symptoms. Perhaps these individuals simply do not remember that they recognized symptoms. Perhaps patients could not reach effective self-management decisions secondary to deficits in problem solving and executive function. Does the presence of CI predict mortality, or does it predict inability to perform self-care, leading to increased mortality? At any rate, it is apparent that CI leads to real-life consequences, to less than optimum outcomes.

To be sure, the phenomenon of CI in HF has been widely studied. The same can be said for the phenomenon of self-care in HF. A complete review of the current literature in these areas will follow in the subsequent chapter. While these are both areas that are frequently studied, there is little knowledge associating self-care with CI in patients with HF. Theoretically, it would seem that impairments in memory, learning, attention, insight and executive function would impair an individual's ability to participate in self-care behaviors, particularly considering the emphasis placed on symptom recognition, symptom evaluation and decision making in the self-management process.

Significance/Research Question

While it is important to know if specific physiologic variables predict or are otherwise associated with CI in HF, it is this author's opinion that it is equally important to understand the real life consequences of this phenomenon in this population. Are those individuals with HF and CI less able to take care of themselves than those without CI? Are they more likely to be readmitted after a hospitalization than those without CI? That being said, the primary aim of the study was to examine the relationship between cognitive impairment (as manifested by deficits in memory, attention, learning, executive function and insight) and self-care ability in patients with HF. Secondary aims of the proposed study were to examine the relationships between cognitive impairment in HF and readmissions and self-care.

The specific research questions are:

1. Is cognitive impairment in heart failure patients associated with decreased ability to perform self-care?
2. Is decreased ability to perform self-care in heart failure patients associated with increased readmission days? and
3. Is cognitive impairment in heart failure patients associated with increased readmission days?

This study will provide clinically relevant information to health care providers who care for patients with HF. By adding to the body of knowledge already available in this area, care providers may be better prepared to recognize, evaluate for, and perhaps most importantly, assist the patient to compensate for impairment in memory, learning, attention, insight and executive function. Assisting patients to improve on self-care techniques will ultimately lead to improved quality of life and less hospitalizations.

CHAPTER TWO

REVIEW OF THE LITERATURE

Introduction

In the previous chapter, both the phenomena of self-care in HF and CI in HF were introduced. Despite the fact that self-care plays an important part in the day-to-day management of HF, patients with this chronic illness may lack the ability to effectively participate in self-care. Cognitive impairment in HF is a relatively frequent occurrence, and may impact the individual's attempt at successfully managing their condition. Although both the phenomena of CI in HF and self-care in HF have been widely studied, only one study to date has drawn any association between these two variables. The purpose of this chapter is to define cognition and domains of cognition, develop a conceptual framework for the proposed study, to briefly review the literature relative to CI in HF and self-care in HF and to review the psychometric properties of the instruments utilized for this study.

Cognition and Cognitive Impairment

In order to fully understand the nature of problems specific to CI, one must first understand the concept of cognition and the domains of cognition. Cognition, according to *The American Heritage Dictionary*, is broadly defined as “the mental process or faculty by which knowledge is acquired” (Morris, 1980, p. 259). Riegel, et al. (2002) define cognition simply as “those mental activities associated with thinking, learning and

memory” (p. 522). Cognition is also broadly defined in the *Iowa Outcomes Project Nursing Outcomes Classification (NOC)* as “the ability to execute complex mental processes” (Johnson, Maas & Moorhead, 2000, p. 170). Roy and Andrews (1999) narrow the definition by attributing a specific human quality, defining cognition as “a broad term encompassing the human abilities to think, feel and act” (p. 320). Still other authors have integrated specific cognitive functions or domains into the definition. According to Bennett & Sauve (2003), cognition is “central to functioning and it encompasses a range of activities and behaviors that include biological and neurological functioning, sensation, perception and emotions” (p. 220).

Although the nature of human thought can be more or less broadly defined as cognition, cognition is itself, composed of many distinct, yet interrelated functions, or domains of cognition. For example, memory, as previously described, is the ability to remember information and later use it for specific purposes (Lezak et al., 2004). Memory can be further described as long-term or short-term memory. Long term memory, or learning, refers to the process of perceiving and storing information for later use, while short term memory involves the storage of information for almost immediate use, perhaps minutes or even seconds after the information is perceived (Lezak, et al., 2004). The domain of thinking or reasoning, as discussed, is the process where two or more stored items of information may be linked together. Reasoning may include functions such as abstract reasoning, complex reasoning, concept formation, and problem solving (Lezak et al., 2004). However, in order to link stored items together, they must be recalled or recognized. Recall refers to the ability to bring to consciousness those items learned

(stored in memory) at an earlier time (Matlin, 1994). Alternatively, recognition refers to the ability to identify an object or concept that has previously been learned (Matlin, 1994).

There are other important aspects, processes or domains of cognition. For example, attention refers only to the organism's ability to receive information, not the process of storage or retrieval. Selective attention, also called concentration, refers to ability to focus on a limited, and usually small, number of items while suppressing other items in the background (Lezak et al., 2004). Orientation is an awareness of one's place relative to their surroundings (Lezak et al., 2004).

Recently, neuropsychologists have recognized the domain of insight, which is a type of self awareness (Lezak, et al., 2004). As discussed, in the common sense, insight is the ability to understand the "true nature of a situation" (Morris, 1980, p. 679). However in the neuropsychological sense, the term insight is frequently used to refer to an individual's perception of their own mental illness. In fact, measurement tools used to assess insight typically involve measurement of insight in schizophrenic symptoms. Insight usually involves an awareness of the presence of a psychiatric disorder, awareness of the symptoms of the psychiatric disorder or finally, awareness of the need for treatment of symptoms of the disorder (Karow & Payonk, 2006). Despite the fact that insight refers to mental disabilities, neuropsychologists use the term anosognosia to refer to insight specifically in relation an illness or disability (Kolb & Whishaw, 2003; Lezak, et al., 2004). Kolb and Whishaw (2003) define anosognosia as "unawareness or denial of

illness” (p. 356). Migliorelli, et al. (1995) include misinterpretation of the illness in their definition, while Lezak et al. (2004) define anosognosia as “impaired awareness of one’s own disability or disabled body parts” (p. 288).

Finally, executive function is a complex activity describing the ability of a person to adapt to situations. Performance of this higher level of cognitive function involves judgment, planning, performance, reassessment and readjustment of activity. Executive function forms the basis of socially responsible, adult behavior (Katz & Harman-Maeir, 1997; Lezak, 2004). Katz and Hartman-Maier (1997) believe that executive functions and awareness “control and regulate activities in all domains of life” (p. 54), and feel that these higher order metacognitive functions are a necessary component in adjusting to an illness or disability. Metacognition is a complex, integrated activity that requires the organization of many cognitive skills.

The integrated, complex nature of executive function as a metacognitive function can be illustrated in a study performed by Pineda and Merchan (2003). In this study, the investigators sought to characterize the nature of executive function by administering a battery of executive function tests to 100 Columbian college students. The battery of tests included the Trail Making Test part A and part B, the Wisconsin Card Sort Test, Stoop’s conflict work/color test and a verbal fluency test. Exploratory factor analysis confirmed five factors in an orthogonal varimax rotation. These five factors were organization and flexibility, sustained attention, speed for inhibitory control, visual-motor

speed and verbal fluency. A list of domains of cognition with associated definitions are listed in Table 1.

Table 1. Definitions of Cognitive Domains

<i>Cognitive Domain</i>	<i>Definition</i>	<i>Source</i>
Anosognosia	Lack of self awareness as it relates to an illness	Kolb & Whishaw (2003)
Attention	The ability to receive information.	Lezak et al. (2004)
Executive function	An integrated activity describing the ability of a person to adapt to situations.	Lezak et al. (2004)
Insight	Self awareness, usually of mental illness. Involves awareness of illness, symptoms and treatments necessary.	Lezak et al. (2004)
Learning	The ability to retain information.	Lezak et al. (2004)
Memory	The ability to remember information and later use it for specific purposes. May be short or long term.	Lezak et al. (2004)
Orientation	The awareness of oneself relative to one's surroundings.	Lezak et al. (2004)
Perception, auditory	The coding of data received via the sense hearing into meaningful information.	Lezak et al. (2004)
Perception, visual	The coding of data received via the sense sight into meaningful information.	Lezak et al. (2004)
Recall	The ability to bring to consciousness those items stored in memory.	Matlin, 1994
Recognition	The ability to identify an object or concept as one that has been previously stored in memory.	Matlin, 1994
Thinking or reasoning	Process of linking two or more stored items of information.	Lezak et al. (2004)

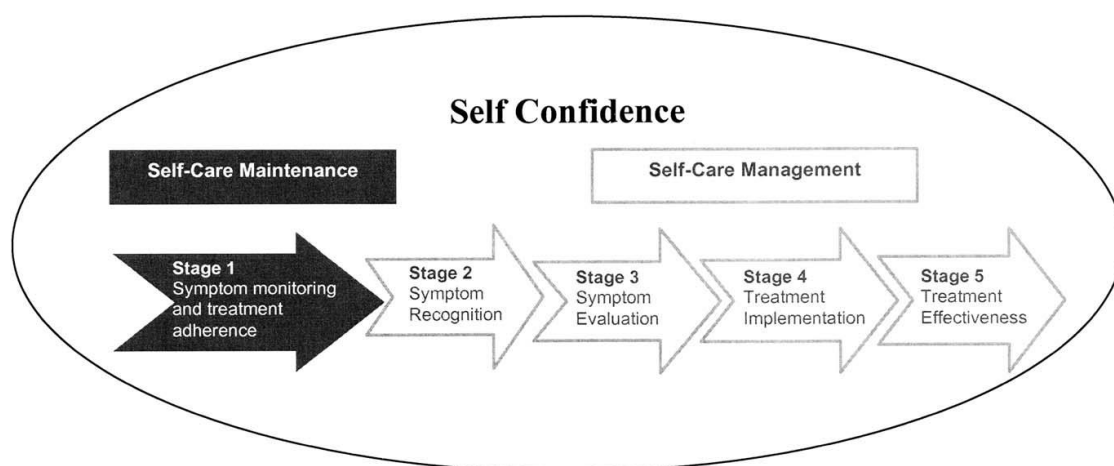
Despite the fact that domains of cognition represent somewhat clear and defined activities, these activities are highly interrelated and interdependent on each other. Cognitive impairment, as defined earlier, may affect one or more domains in cognition, and may manifest itself as ability below group norms, below previously held levels or below a normal control group. Assessment of these highly interrelated specific cognitive functions may be problematic in many situations.

Conceptual Framework

The development of scientific knowledge in nursing, as in any discipline, depends upon the development of concepts and subsequently, the development of a conceptual model or framework. Imogene King (1997) defined concepts as “abstract representations of an individual’s comprehension of persons, objects and events” (p.11). Concepts allow individuals to parcel abstract knowledge into categories and link these categories together into a meaningful system. These conceptual systems, or conceptual frameworks, allow the person to narrow thinking about specific concepts and provide a mechanism to guide subsequent knowledge development (King, 1997). States Fawcett (2000): “Each conceptual model gives direction to the search for relevant questions about the phenomena of central interest to a discipline” (p. 16).

Many nursing authors have studied the phenomenon of self-care in HF. One of these researchers, Barbara Riegel, has developed the Self-Care of Heart Failure Index (SCHFI), which is designed to measure self-care activities in HF. This index was based on a five stage conceptual model. (See Figure 1 below)

Figure 1. Conceptual Model of the Self-Care Process



Reprinted from Journal of Cardiac Failure, Vol 10, B. Riegel, B. Carlson, D. Moser, M. Sebern, F. Hicks, and V. Roland, "Psychometric Testing of the Self-Care of Heart Failure Index" p. 352, 2004, with permission from Elsevier, Inc.

Riegel's model is based on the principles of naturalistic decision making.

Naturalistic decision making is a theoretical framework developed in 1989 that is used to explain decision making processes as they occur under specific conditions. These conditions are "time, pressure, uncertainty, ill defined goals, high personal stakes and other complexities" (Lipschitz, Klein, Orasanu & Salas, 2001, p. 332). The person making the decision is at the center of the framework, and there is an emphasis on the manner in which previous experience is used to make decision in real-life situations. This framework has been used in training various professions for real-life activities, and has been studied with critical incident response teams, firefighters, naval officers, air crews, medical teams and nurses (Lipschitz et al., 2001).

As previously described, Riegel views self-care as a dual process of self-maintenance and self-management behaviors. Self-maintenance involves those activities

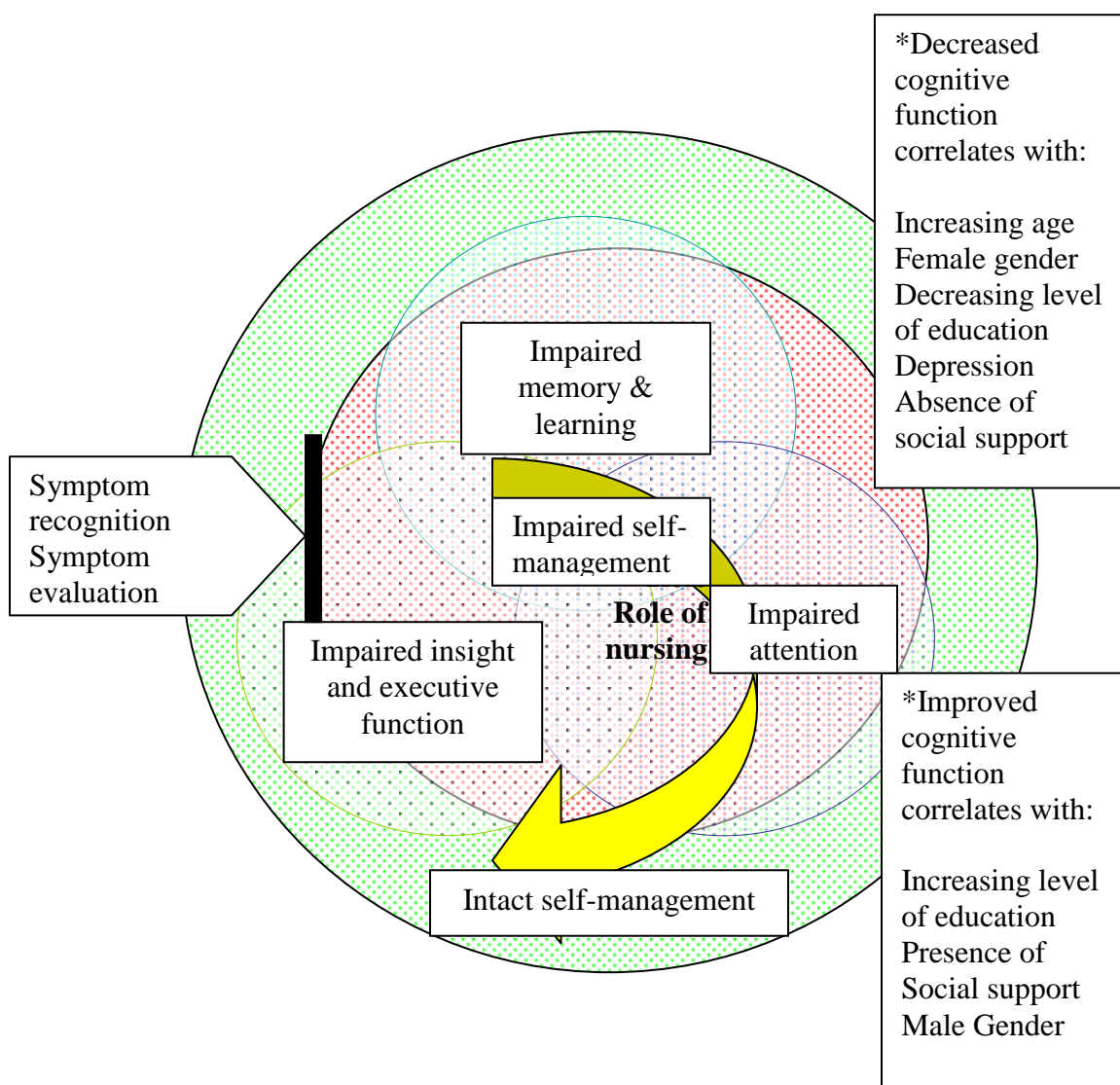
that maintain relative health or a healthy lifestyle. Self-maintenance activity in HF would include taking prescribed medications as ordered, exercising, monitoring vital signs and weight and, cessation of smoking. Self-care maintenance is depicted by the black arrow in Figure 1 above. Self-management, on the other hand, includes those activities aimed at restoring relative health, which in HF would include adjusting doses of diuretics, notifying a healthcare provider in response to symptoms, evaluating the response to the change and making appropriate readjustments in therapy. As depicted in Figure 1 above, symptom recognition is the critical first step in the self-management process. Each step in the decision making process depends on the previous step for success, so inability in any step will limit the process. If symptoms are not recognized, the process stops. If symptoms are recognized, but judged to be unimportant, the process stops. If treatment is not decided upon or implemented, the process will likewise, terminate. All of these conditions could have disastrous ramifications to an individual with HF.

The naturalistic decision making framework has important parallels to self-care in HF. First of all, the specific conditions surrounding the decision making process, such as time, pressure, uncertainty, high personal stakes and the complexity of the illness itself are evident in this decision making process. Individuals who make poor decisions may be hospitalized or even die, elevating the personal stakes involved. The element of time is also important, as patients understand that symptoms may progress quickly if appropriate intervention does not take place. Finally, the person with HF is at the center

of the decision making process, and must draw upon past experiences to formulate new, pertinent decisions.

Although this model proposes a comprehensive framework for decision making in self-care for individuals with HF, it does not allow for difficulties related to CI. As described in the previous chapter, CI in HF is widely prevalent, and includes known impairment in memory, attention and learning. To what extent is an individual with HF and CI able to use past experiences to guide decision making? Similarly, the domains of insight and executive function have not been widely studied. Can individuals with poor insight appreciate and evaluate symptoms effectively? Can individuals with limited ability in executive function evaluate past responses to formulate current decisions? When pondering these thoughts, this author developed a model of CI in HF that is depicted below in Figure 2.

Figure 2. Murks' Model of Self Management in Heart Failure



In the proposed model, impairment in memory, learning, attention, insight and executive function affect the performance of self-care, as depicted by the conjoined circles at the center of the model. While specific minor impairments in these domains may not affect self-care performance (as evidenced by their overlap to the outer ring, intact self-management), severe deficits in one or more of these domains limit the ability

of the individual to perform self-care. As in Riegel's model, symptom recognition and symptom evaluation are integral parts, depicted by the arrows on the left side of the model. However, notice that the arrow depicting symptom recognition and symptom management is blocked by a solid black line, and does not penetrate the inner circle. This indicates that individuals with cognitive impairment may not perceive, recognize or evaluate symptoms. Inability to recognize or evaluate symptoms will cause failure of the self-management model. Finally, the role of nursing, represented by the curvilinear arrow, is to reduce the effects of cognitive impairment on self-management and to assist individuals to meet their self-care goals.

Self-Care in Heart Failure

There is a plethora of nursing research in the area of self-care in HF. Over the years, nursing researchers have sought to describe the experience of living with heart failure, to describe self-care techniques, to elucidate barriers and aids in performing self-care, to describe interventions to assist in self-care and to develop tools to measure various aspects of self-care.

Living with Heart Failure

As described previously, living with HF places a huge burden on both the individual with HF as well as the caregivers. Much of the work in this area has been briefly discussed in Chapter One, however, it will be discussed in more detail to follow. One of these studies was a qualitative study that set out to describe the symptoms of individuals with HF, describe the methods used by individuals to manage their HF

symptoms, and to classify these methods. In this study, Bennett et al. (2000) interviewed 23 participants and 18 participant caregivers in focus groups. Participants reported many bothersome symptoms, including shortness of breath, swelling, memory loss, difficulty concentrating, loss of balance, chest pain, fatigue, difficulty sleeping, loss of weight, and difficulty with position changes. Participants also reported sleep interruptions and social isolation related to diuresis. Women, in particular, described emotional distress such as fear, anxiety and depression, while men reported a lack of interest in sexual activities. Caregivers described that they often took over tasks for the individual with HF, such as driving the patient to appointments and tests.

Similar findings were reported by Bennett et al. (1998) in a study of 30 women with HF. Participants in this study were administered the Minnesota Living with Heart Failure Questionnaire, the Alertness Behavior Scale of the Sickness Impact Profile, the Medical Outcomes Study Short-Form Health Survey, and the Medical Outcomes Study Social Support Survey. The purpose of the study was to describe the symptoms most often affecting quality of life in women with HF and to determine the relationship between symptoms, support, health and quality of life. In addition to the physical symptoms of fatigue and dyspnea previously described, participants reported social problems such as difficulty in relating to peers. Participants found it challenging to leave the home and participate in social activities. Finally, these women expressed difficulties in performing previously held responsibilities, such as household duties, because they needed to take frequent breaks to rest.

Many of these themes in addition to others, were expressed in a qualitative study by Brannstrom, Ekman, Norberg, Boman and Strandberg (2006). In this study, five patients were interviewed in their homes, the audiotaped interview was transcribed and data was interpreted by the phenomenological-hermeneutic methodology. In addition to feelings of uncertainty with one's own body and feelings of one's own mortality, participants reported difficulty in dealing with loneliness and isolation and feeling dependent upon another. Focused interviews of ten patient/caregiver dyads were performed by Aldred, Gott and Gariballa (2003). These interviews also took place in the participants' home with both the patient and caregiver present. Interviews were taped and transcribed, and data analyzed to extract themes. Participants described the impact HF had on their life and their relationships, with both caregivers and patients describing social isolation as having a negative effect on their lives. As described in other studies, symptoms of HF prevented them from participating in social activities, leading to loneliness and isolation. These studies emphasize the wide impact of symptoms and the associated distress individuals with HF face, including CI. However, symptom burden is not the only factor affecting the lives of individuals with HF. To be sure, HF imposes a significant burden on individuals, not only in terms of symptoms, but also in terms of social isolation and quality of life.

Self-Care Techniques

Many nursing researchers have sought to describe the experience of self-care (both in terms of self-maintenance and self-management) in individuals with HF. One of

these studies, the study by Bennett et al. (2000), has been previously described in relation to symptom burden, however an additional objective of this study was to describe the activities performed by participants while managing their symptoms. The participants in the study described 11 activities: altering physical activity patterns, breathing assistance, medication management, using assistive devices, adherence to a low sodium diet, monitoring for signs and symptoms of heart failure, activities to help with sleeping, enlisting support from family members and positive self assurance. Assistive devices, such as medication lists or other reminders were designed to assist patients with memory impairments to maintain self-care behaviors. Additionally, caregivers who recognized cognitive decline assumed responsibilities for selected self-care activities, such as shopping and driving patients to physician visits.

However, not all patients with HF perform self-care activities as described above. In another study, Artinian et al. (2002) described the incidence of self-care activities and the factors affecting self-care activities. In this study, 110 participants (86 males, mean age 64 years) described frequency of self-care activities by self-report methodology. The most frequently performed activities involved taking prescribed medications, visiting the physician as advised, and keeping a positive attitude. Alternatively, the least frequently performed activities involved physician notification for symptoms of volume overload, weighing self, and following a fluid restriction. Older participants were more compliant with medications and physician visits, while younger participants were more likely to notify the physician about symptoms.

Yet another study to describe activities of self-care was performed by Carlson, Riegel and Moser (2001). The Self-Management of Heart Failure Questionnaire was used to describe the activities of self-care in HF and to determine if time since diagnosis of HF impacts self-management activities. One hundred twenty nine elderly (mean age 69.7 years), men (53.2%), were recruited for the study during hospitalization for HF exacerbation. Most participants were retired (73%), and married (45.3%) or living with someone (2.9%). In this hospitalized group, most participants reported that they had experienced weight gain, lower extremity edema, orthopnea, or fatigue, but did not believe these symptoms were due to HF. Participants with a longer duration of HF did find it easier to recognize symptoms, however, symptom recognition was problematic, even in this group. Similarly, in those participants who identified the symptoms, appropriate self-management activities ensued 32-99% of the time, depending on the symptom and activity. For example, only 33% of participants reduced dietary fluid intake when they experienced lower extremity edema, but 99% responded to fatigue by utilizing rest periods. Although most participants were unable to recognize symptoms of HF, most participants felt either very confident or extremely confident in areas of symptom recognition and evaluation, intervention and reevaluation. It is important to consider the self-care activities described in this study carefully. Responding to fatigue may be more a reflexive activity than a conscious decision, so adherence in this self-care behavior speaks less to decision making and more to common sense. On the other hand,

consciously deciding to reduce fluid intake in response to symptoms represents an active decision making process.

In another study, Rockwell and Riegel (2001) attempted to determine if participant characteristics predicted the ability to successfully perform self-management in HF with specific focus on symptom recognition. The researchers utilized the Evaluating the Change subscale of the Self-Management of Heart Failure Instrument to determine if participants in the study could recognize and evaluate symptoms of HF should they occur. Two hundred nine participants with HF were recruited for the study during a hospitalization. Participants were elderly, with a mean age of 73, and evenly distributed by gender. Scores on the subscale were correlated to patient characteristics such as comorbid conditions, level of education, age, gender, socioeconomic status, severity of symptoms and support of others. When taken together, these variables explained only 10% of the variance in the Evaluating the Change subscale scores during multiple regression analysis. Only level of education and symptom severity were significant predictors in this model, accounting for 4.6% ($p = .009$) and 2.7% ($p = .046$) of the variance respectively.

Adherence to self-care activities was also studied by Schweitzer, Head and Dwyer (2007). The researchers hypothesized that depression, anxiety and self-efficacy would predict adherence to seven self-maintenance activities. Adherence to self-maintenance activities was measured by the SCHFI as well as a questionnaire developed specifically for this study. The seven self-maintenance activities included weighing oneself daily,

following a sodium restriction, following a 1500 cc fluid restriction, taking prescribed medications as ordered, participating in exercise, avoiding smoking and avoiding alcohol. In the final analysis, depression did not predict adherence to any activity, and anxiety predicted only minimal adherence to avoiding smoking and alcohol (14.2% and 3.4% of the variability respectively). However, self-efficacy predicted 13.1% of the variability in weighing oneself, 15.5% of the variability in limiting sodium intake, 6.1% of the variability in limiting fluid intake, 11.8% of the variability of participating in exercise, 14.2% of the variability in avoiding smoking and 24.3% of the variability in avoiding alcohol. None of the variables predicted taking prescribed medications as ordered, despite the fact that this activity had the highest level of self reported adherence. It is clear from the results of these last two studies that current knowledge does not allow for prediction of success in self-care performance. Neither does depression, anxiety, age, gender, socioeconomic status nor social support predict ability to perform self-care.

To be sure, the process of self-care in HF is complicated. Patients must assimilate information on many levels and from many providers, as well as perform activities of self- management. Patients seem willing to comply with relatively simple tasks, such as taking medications as prescribed and visiting the physician as ordered, but many fall short in more complex activities, such as symptom recognition, symptom monitoring, symptom management, and decision making regarding self-care management activities. What determines an individual's ability to perform self-care?

Barriers and Aids in Performing Self-Care

Many nursing researchers have attempted to answer this question. Barriers in the performance of self-care may be related to knowledge deficits, symptom recognition or social isolation. On the other hand, measures to improve self-care performance include adaptive mechanisms and self-efficacy.

Knowledge Deficits

In a qualitative study, Riegel and Carlson (2002) attempted to describe factors that support or impede self-management in heart failure. The investigators audiotaped focused interviews of 26 participants and used content analysis techniques to analyze the data. Participants identified several themes previously described by others living with heart failure, such as decreased endurance, the demands of therapy, troubling emotions, knowledge deficits, other illnesses and life stressors as daily obstacles. Participants also endorsed difficulty with symptom recognition and medication adherence as barriers to self-care. Many study participants described the development of adaptive memory aids to promote medication adherence, such as medication lists and schedules. Participants also discussed utilizing assistive devices, enlisting the support of others and making lists of questions prior to an office visit so as to adapt to difficulty with physical and cognitive deficits. These findings are similar to the focus group study of Bennett et al. (1998), where participants developed specific memory aids to assist them in self-care activities.

Knowledge deficits in the area of self-care were explored in a study by Ni et al. (1999). These investigators set out to explain differences in self-care behaviors in person

with HF, to describe the level of knowledge of HF self-care and to determine if knowledge of HF self-care behaviors impacts the performance of self-care behaviors. A total of 113 participants with a confirmed diagnosis of HF were recruited from an outpatient clinic. The participants were young (mean age 51 years), mostly males (66%) and Caucasian (87%). Knowledge of self-care was measured by an investigator designed survey which included 16 questions that could be answered either in a true/false or yes/no method. Participants were also asked if they were ever told about self-care, and if so, by whom. Symptoms were reported similarly, with participants indicating if they had ever experienced any number of symptoms including shortness of breath, weight gain, nausea and depression. If participants indicated they had in fact experienced these symptoms, participants were then asked if the healthcare provider was notified. Adherence to self-care was assessed by self-report as well, with an eight item survey covering areas of adherence to prescription medications, sodium restrictions, and daily weight measurement. Although a majority (71%) of participants indicated that they had been informed about HF self-care, most indicated that they knew some (48%) or little or nothing (38%) about their own care. This was borne out in the area of symptom recognition, as 37% did not recognize weight gain and 52% did not recognize nocturia as symptoms of worsening HF. Similarly, 20% of participants did not know daily sodium allowance and 25% of participants did not know they should abstain from alcohol. On the other hand, most participants (74%) indicated they took their medications as prescribed, while some (25%) indicated they took their medications most of the time.

Alternatively, adherence to other behaviors, such as weight monitoring, was worse, with only 57% of participants reporting adherence to daily weight monitoring and only 38-40% of participants reporting that limiting dietary sodium was important actually limiting sodium intake. Despite the relatively low adherence to self-care behaviors, the knowledge score was significantly though weakly correlated with the adherence score ($r=0.33$, $p<.001$). After controlling for knowledge scores, multiple regression analysis revealed that poor adherence to self-care activities was associated with being single, decreased self-efficacy, a lack of knowledge of self-care, no previous hospital stay, and care by someone other than a cardiologist.

While knowledge may be an important factor in self-care performance, several studies have recognized the role of self-efficacy in self-care. Self-efficacy is an important feature in Riegel's self care model and was also identified as promoting adherence to self-care behaviors in the study by Schweitzer et al. (2007). However, previous studies have shown that despite the fact that patients did not recognize symptoms of HF, they were confident in their self-care abilities (Carlson et al., 2001). This is a potentially hazardous situation, as symptom recognition is the key to the self-management process. Individuals who fail to recognize symptoms yet feel secure in their self-management practices may not effectively manage their disease.

Rogers et al. (2002) performed a qualitative study aimed at describing the medical management and analysis of symptoms in patients living with heart failure. A total of 27 participants (20 male, 21 caucasian, mean age 69) with HF were interviewed at their

home. Interviews were taped recorded and constant comparative analysis techniques were used for analysis. Four key areas emerged: reason for individual drug therapy, apprehensions about drug therapies, differentiating between side effects of drug therapy and HF symptoms, and analysis and actions related to symptoms of HF. Although participants had a basic understanding of their heart problem, they had little or no knowledge of drugs in their regimen with the exception of diuretics. Participants were concerned about the number of drugs they were prescribed, dosages, interactions, and information they read on package inserts. Participants reported 19 symptoms as troublesome, many of which have been described previously, that included shortness of breath, fatigue, chest discomfort, difficulty sleeping, depression, memory loss and anorexia. Many participants expressed problems in differentiating between symptoms of HF and side effects of medications. Finally, participants reported anxiety over symptom interpretation, particularly in determining when to consult a physician about symptom change. The authors concluded that participants in this study lacked basic knowledge of heart failure, such as symptoms as indicative of disease and actions of drugs used to treat HF.

A similar qualitative analysis was performed by Horowitz, Rein and Leventhal (2004), who set out to describe the knowledge and beliefs held about HF by participants with HF, and to understand self-management techniques utilized by these individuals. It was ultimately hoped that by understanding these techniques, self-management techniques could be improved. Semi-structured interviews were used on the 19

participants and data analysis was performed utilizing a constant comparative approach. Three common themes emerged: lack of knowledge relative to HF; lack of resources to approach exacerbations of HF before decompensation and; difficulty in accessing healthcare systems short of the emergency room. Participants in this study, it would seem, lacked the knowledge to both interpret symptoms and associate symptoms with HF, lacked the ability to discern worsening symptoms, lacked the ability to avert exacerbations of HF, and lacked the ability to participate in a complex health care system.

At this point, it is important to consider the model of self-care in HF proposed by Reigel. As described, symptom recognition forms the first and most critical step in the self-management process. Subsequent self-management activities depend upon recognition and evaluation of symptoms. Yet, a common finding in the previously described studies is difficulty in symptom recognition, symptom interpretation and symptom management. In some studies, this was associated with a lack of knowledge of HF, however, in other studies, participants expressed that they had been educated about HF, yet they failed to recognize symptoms of exacerbation. Why do patients who were educated about HF still fail to recognize symptoms? It would seem that successful self-care performance does not rest only on patient education. Previous studies have demonstrated the importance of self-efficacy in self-management, but some patients with poor symptom recognition demonstrate high self-efficacy. On the other hand, patients who recognize symptoms may fail to act on them appropriately. It is certainly true that there is no specific answer to the question relating to inabilities in self-care management.

It behooves the profession of nursing to develop the nursing knowledge required to facilitate these behaviors.

Symptom Recognition

Difficulties associated with symptom recognition were studied by way of symptom delay in several investigations. In one of these studies, Friedman (1997) retrospectively reviewed the hospital charts of 181 patients admitted with HF. The investigator wished to determine the type and duration of symptoms prior to admission and discovered that dyspnea was the most frequently reported symptom, present in 91% of all patients, followed by acute dyspnea in 37%. Interestingly, the duration of dyspnea prior to admission was three days, and the duration for acute dyspnea was 12 hours. These results were replicated in a study by Evangelista, et al. (2000), who also retrospectively reviewed the hospital records of 753 patients admitted with HF. Dyspnea was reported by 76% of study participants, edema by 66%, fatigue by 37%, and angina by 25%. Average duration of delay was 2.93 days. Similar to Friedman's study, Evangelista et al. determined that the presence of dyspnea and edema increased delay time, while presence of chest pain decreased delay time. Could failure to recognize the symptom of dyspnea and edema account for treatment seeking delay? Can patients hospitalized with HF accurately describe their symptoms, including their duration?

A group of nursing researchers discovered an association between perceptions of dyspnea and cognitive function in 145 outpatient participants with heart failure. Hou et al. (2000) used the Short Portable Mental Status Questionnaire (SPMSQ) to evaluate the

cognitive performance of participants. Test scores, age, gender, race, education, NYHA classification, of comorbidity, and quality of life were entered into a multiple regression analysis. Lower cognitive performance was correlated to lower education, African American race, and less reported dyspnea symptoms. These findings appeared despite the fact that cognitive performance as measured by the SPMSQ focuses heavily on the domain of orientation (Lezak, 2004), which may not reflect most abilities necessary in performance of self-care. The investigators were surprised by this relationship and suggested further research to describe this association more fully.

Finally, the concept of expertise in HF self-care was examined in a study by Riegel, Dickson, Goldberg and Deatruck (2007). In this mixed-methods study, qualitative data was collected through interviews with the participants and quantitative data was collected on comorbidities, self-care activities, cognitive status, sleepiness, social support, depression and functional class. The Charlson Index, the SCHFI, the Probed Memory Recall Test, the Digit Substitution Test, the Epworth Sleepiness Scale, the McMaster Family Assessment Device, the Patient Health Questionnaire and the New York Heart Association Functional class were used to quantify the variables of interest. Participants were rated by examiners as poor, good or expert in self-care using interview data and field notes to rate the participants. Twenty-nine participants were interviewed, yet only three were rated as experts in self-care during qualitative interviews. On the other hand, 16 were classified as good in self-care and 10 were rated as poor in self-care. Variables that predicted poor self-care were poor memory, attention and cognitive

processing, sleepiness during the day, depression and poor family support. Those who were rated as experts in self-care had less sleepiness during the daytime and more family support. While it is important to note that there is a relatively small number of individuals who were judged to have expert status, it is equally important to note that impaired cognitive status predicted poor self-care ability. It is this author's belief that this study and the above study are the only studies that associate the phenomenon of self-care with the phenomenon of CI.

Perhaps the findings of this study help provide some insight into both the concept of symptom management and the concept of treatment delay. Those individuals who were considered to be poor at self-care had higher levels of depression, impaired memory, impaired attention and impaired cognitive processing. On the other hand, participants in the studies regarding treatment seeking delay were hospitalized. Were these patients hospitalized because they lacked the ability to recognize, interpret and evaluate symptoms? Clearly, these individuals were able to report a duration of symptoms prior to admission, so it is reasonable to assume that symptom recognition took place. But why, then, did participants delay in seeking care? Did they lack the ability to reach decisions? Were they unable to draw upon previous experiences in self-care? Were there access issues? Did patients just not have adequate support to enter a health care system? Although symptom recognition is a key part of the self-management process, self-management still requires decision making and treatment implementation.

Cognitive impairment may affect the ability of an individual to perform self-care at many points along the model, depending on the particular domain of cognition that is impaired.

Social Isolation

As previously stated, HF is a disease of the aging. There is a growing body of literature addressing the psychosocial issues in the elderly, including those with HF. One of the psychosocial issues explored is the problem of social isolation, and the significant effect this phenomenon has on both readmissions for HF and mortality in HF.

The experience of living with HF has been previously described. Many studies have described social isolation, role reversal, and symptom distress. Social isolation may have a negative effect on the lives of individuals with HF, as ability to perform self-care can be impacted by social isolation. Inability to obtain support may mean that individuals lack sufficient supplies of medications, transportation to healthcare provider visits and assistance with self-care activities. Findings such as these have led to the inclusion of social isolation measures in studies of readmission and mortality in HF.

As stated previously, readmission rates for HF are high, with 44% of patients requiring readmission within six months of discharge (Krumholz et al., 1997). Medical and nursing literature has reported factors contributing to readmission in HF in an effort to develop interventions to reduce readmissions. Happ, Naylor and Roe-Prior (1997) examined the patient logs of advanced practice nurses to describe patient interactions in HF. Hospital records were also examined for descriptive data. The investigators determined that a majority of patients required readmission due to problems with

compliance with medications, diet or physician visits. While lack of social support was not specifically implicated in these behaviors, social support was identified as a factor that prevented readmission.

On the other hand, Chin and Goldman (1997) were able to demonstrate a direct relationship between readmission or death in a group of 257 patients admitted to a large university based hospital. In this study, single marital status was significantly correlated with death and readmission. This was not, however, duplicated in a study by Bennett, Pressler, Hays, Firestine and Huster (1997). Sixty-five outpatients were examined for a six month period. Of the original 65 patients, 37% (23) were admitted to the hospital at least once during the study period. Perceived social support was measured by Medical Outcomes Survey, Social Support Survey, and no association was demonstrated between perceived social support and hospital admission.

Despite the contradiction in studies pertaining to readmission, the effect of social isolation on mortality is clear. Murberg and Bru (2001) used proportional hazard models to examine the effects of social support and social isolation on mortality in HF. After controlling for age, depression, NYHA class, and brain natriuretic peptide levels, social isolation significantly predicted mortality with a relative risk ratio of 1.5. With the exception of brain natriuretic peptide levels, no other variables had significant predictive ability. This was supported in a study by MacIntyre et al. (2000), who performed a retrospective analysis of a large data set in Scotland. Social isolation scores were derived from a model taking into consideration census data on overcrowding, access to

transportation and socioeconomic class. Social isolation scores ranged from one to five, with one being the least deprived and five being the most deprived. Those persons in the highest quintiles of the sample (most social isolation) accounted for 44% of the deaths in the study population. Finally, the medical records of 292 patients hospitalized with HF were examined by Krumholz et al. (1998). Readmission rates were high among this group, with 49% being readmitted within one year. Lack of social ties and lack of emotional support predicted serious cardiac events, either fatal or nonfatal, for the 12 months after discharge in stepwise multivariate logistic regression (OR 2.08 and 2.69 respectively). Other significant predictors were male gender, $EF \geq 55\%$, myocardial infarction at admission, history of hypertension, and level of acute decompensation.

To be sure, the effect of social isolation on outcomes in HF is profound. Social isolation may affect self-care ability, hospital utilization and mortality. Studies performed to date describe a strong association between social isolation and readmissions and mortality. Despite this association, little has been done in the way of interventions to improve these consequences.

Interventions to Improve Self-Care

Much of the scientific literature in nursing has recently focused on interventions designed to promote self-care, reduce resource utilization and to improve quality of life. These interventions have ranged from simple diary type recording to elaborate symptom management programs.

One very simple mechanism studied involved the utilization of a diary to record weight, vital signs and symptoms on a daily basis. In this study by Eastwood, Travis, Morgenstern and Donaho (2007), a total of 124 patients were given the diary, 70 of which used the diary and 54 who did not. Those who used the diary differed from those who did not in ejection fraction (EF) (diary users higher), New York Heart Association Class (NYHA) (diary users higher), and brain natriuretic peptide (diary users higher). There was no difference between groups in age or gender. After six months, diary users had an improvement in EF ($p<.038$), NYHA ($p<.001$) and brain natriuretic peptide levels ($p<.011$), while nonusers had improvement in NYHA ($p<.001$) and brain natriuretic peptide levels ($p<.004$). However, diary users had more telephone contacts and clinic visits than nonusers ($p<.007$ and $p<.001$), but decreased length of stay for subsequent hospital admissions than nonusers. While it is unclear why diary users had significantly more telephone calls and office visits than nonusers, it is quite possible that diary users called or visited the healthcare provider for validation of self-management decisions. On the other hand, they may have lacked the ability to make any level of decision regarding self-management, and needed to report signs and symptoms in order to obtain further direction in their care. Despite the fact that diary users utilized more outpatient services, when hospitalized, diary users had a significantly shorter length of stay, indicating some degree of success in self-management.

Still other approaches to improving self-care have been studied. Motivational counseling, an approach to improving behavioral change through education and

assessment in a non-confrontational manner, was used to increase motivation to perform self-care activities (Riegel, et al., 2006). Specific learning interventions included readings, role playing, open discussions with HF care providers, and home visits. Counseling sessions were designed to allay participant's concerns about change, to assess for readiness for change and to provide the participant with the means to affect change. The SCHFI was used to quantify self-care in the sample of 15 predominately female participants at baseline and again at 90 days after enrollment. There was evidence of improvement in self-care scores in 12 of the 15 participants with improvement in total scale scores by as much as 54 points (Riegel et al., 2006). Despite the fact that self-care behaviors improved, this intervention is resource intensive, with trained motivational counselors making an average of three home visits in the 90 day study period, as well as learning interventions and multiple telephone contacts for follow up. To be sure, this represents an important tool in improving self-care behavior, but it is doubtful that it represents a universal solution.

Another promising intervention revolves around the concept of peer support. Riegel and Carlson (2004) matched 45 hospitalized participants with HF to nine trained mentors. Mentors were trained both in the role of mentor and also in HF self-care by expert clinicians. These mentors were instructed to contact their mentees at least weekly initially after hospital discharge and at least monthly thereafter. An additional 43 participants were assigned usual care and received patient education upon discharge. The SCHFI was used to measure self-care ability at baseline and at 90 days after study

initiation. The intervention group had significantly improved self-management ($p = .04$), self-confidence ($p = .02$) and total SCHFI scores ($p = .04$) at 90 days compared to baseline. The control group did not, however, demonstrate this improvement.

While it may be true that each of the above interventions independently impacted self-care behaviors, it is interesting to note that both interventions involved repeated contacts over a relatively long period of time. Perhaps the type of intervention was not as important as the fact that patients with heart failure were repeatedly provided with opportunities to learn information relative to self-care. Whether the contact is from a health care professional or from a mentor, individuals with HF appeared to benefit by a longer, more drawn out educational process than from simple discharge instructions. Do these interventions represent an improved approach for persons with impairment in memory? Does an individual with HF need to hear information repeatedly to retain it?

Instrument Development

Although the model upon which the SCHFI is based does not consider the role of CI in the self-care process, the model has scientific validity and reliability in the measurement of the phenomenon of self-care in HF. It was initially developed as the Self-Management of Heart Failure instrument, which had 65 items in six subscales (recognizing a change, evaluating a change, implementing a treatment, evaluating a treatment, ease of evaluation and self-efficacy). Pilot testing was performed on 127 English speaking patients, which revealed that subscale internal consistency reliability was generally good (.79 to .92), with a few exceptions. The symptoms of shortness of

breath, sudden weight increases and fatigue in the subscale of evaluating a treatment had internal consistency reliabilities of -.03, .57 and .65 respectively. (Riegel et al., 2000). It was thought that the skip-pattern format and sheer length of the tool confused patients and subjected the patient to undue burden, so the instrument was revised to the shorter SCHFI (Riegel et al., 2004).

The SCHFI is a 15 item tool consisting of three subscales, self-care maintenance, self-care management and self-care self-confidence. Subjects are asked to read the tool and answer the 15 questions on a four-point response scale (Please refer to Appendix B on for a copy of the SCHFI). Complete scoring of the tool is dependent upon symptoms. If a subject has not experienced shortness of breath or ankle swelling in the previous 90 days, he or she is instructed to skip the self-management subscale and proceed to the self-care self-confidence subscale. This self-report ordinal level instrument requires approximately five minutes to complete and is at the 6th grade reading level. Raw scores are transformed into scale scores with a possible score of 100 for each subscale and 300 for the total scale. Higher scores mean higher self-care performance (Riegel et al, 2004).

The SCHFI was tested on a sample of 760 elderly (mean age 70 years), predominately male patients most of whom were diagnosed with HF, on average, two months prior to the testing (69%). Of those 760 participants, only 606 were symptomatic in the previous 90 days and, therefore, had complete scores for the self-care management subscale and the total index. In terms of reliability, total scale $\alpha = .76$, self-care maintenance subscale $\alpha = .56$, self-care management subscale $\alpha = .70$ and self-

care self-confidence $\alpha = .82$. According to Shultz and Whitney (2005) generally, alpha levels of at least .70 are desired to demonstrate internal consistency. Despite the fact that the self-care maintenance subscale had lower than desired reliability, the authors of the tool did not change the integrity of the tool. The authors felt that the variability in scores for this subscale reflected the fact that this subscale measured behaviors that not all individuals with HF are advised to do, such as exercising, or practice regularly, such as getting a flu shot. It was also felt that items in this subscale contributed to the model (Riegel et al., 2004), so this subscale was retained.

Construct validity of the SCHFI was assessed by factor analysis. A subset of 120 symptomatic participants were selected from the larger sample. Confirmatory factor analysis of a three factor model revealed that the model comparative fit index was adequate at .73. Self-care maintenance factor loadings ranged from .21 for “getting a flu shot” to .68 for “weighing yourself daily.” Self-care management factor loadings were also high, ranging from .47 for “calling the doctor” to 1.0 for “how quickly did you recognize and how sure were you that the remedy helped.” Finally, self-care self-confidence factor loadings were also high, ranging from .66 for “evaluating the importance of your symptoms” to .77 for confidence in “evaluating the effectiveness of whatever you choose.” Exploratory factor analysis was also favorable, with four of the five self-care maintenance items loading on one factor with loadings of .34 to .49. These four items explained 23.9% of the variance in the scores. A single item, “getting a flu shot,” did not load with the other four items and was not well correlated with the other

items in the subscale, but loaded at .34 on its own factor. The remaining ten items in the two subscales were also subject to exploratory factor analysis. These ten items loaded on three factors and explained 45.9% of the scores. Each item loaded well (.35 to .83 loadings), but the item regarding recognition of symptoms also did not load with the rest of the self-care management subscale, loading at .62. Despite the fact that the items “getting a flu shot” and “shortness of breath or leg swelling” did not load as expected, each item was retained, as it was felt by the authors that they contributed to the integrity of the instrument.

Finally, construct validity was also evaluated by utilizing a known groups technique. The sample group was divided into two groups, those with a diagnosis of HF of two months or more and those with a diagnosis of HF of less than two months. Statistical analysis of between group differences was performed utilizing t-tests, and significant differences emerged between groups on all the subscales and total subscale scores. Lastly, subscale and total scale correlations were performed and ranged from .17 to .85 ($p < .0001$). Although it would seem that there are some difficulties with specific items in the instrument, this index has adequate reliability and validity for use in clinical research. Please see the tables below for summary of reliability and validity measures.

Table 2. Reliability of Self-Care in Heart Failure Index

<i>Scale/subscale</i>	<i>Alpha</i>
Self-care maintenance	.56
Self-care management	.70
Self-care self-confidence	.82
Total Scale	.76

Table 3. Factor Loadings From Confirmatory and Exploratory Factor Analysis

<i>Items</i>	<i>Self-maintenance</i>	<i>Self-management</i>	<i>Self-confidence</i>	<i>Factor 1</i>	<i>Factor 2</i>	<i>Factor 3</i>	<i>Factor 4</i>	<i>Factor 5</i>
Confirmatory factor analysis				Exploratory factor analysis				
1	.68			.49				
2	.54			.34				
3	.42			.55				
4	.45			.46				
5	.21				.35			
6		1.0				.62		
7		.73					.68	
8		.87					.75	
9		.59					.57	
10		.47					.35	
11		1.0					.45	
12			.66					-.76
13			.75					-.83
14			.72					-.44
15			.77					-.64

Reprinted from Journal of Cardiac Failure, Vol 10, B. Riegel, B. Carlson, D. Moser, M. Sebern, F. Hicks, and V. Roland, "Psychometric Testing of the Self-Care of Heart Failure Index" p. 357, 2004, with permission from Elsevier, Inc.

Table 4. Differences Between Groups

<i>SCHFI mean scores</i>	<i>< 2 months duration of HF</i>	<i>> 2 months duration of HF</i>
Self-care maintenance*	66.1	70.3
Self-care management*	53.4	64.8
Self-care self-confidence*	60.6	66.9
Total scale*	179.5	199.4

* p<.05

Reprinted from Journal of Cardiac Failure, Vol 10, B. Riegel, B. Carlson, D. Moser, M. Sebern, F. Hicks, and V. Roland, "Psychometric Testing of the Self-Care of Heart Failure Index" p. 358, 2004, with permission from Elsevier, Inc.

Table 5. Subscale and Total Intercorrelations

	<i>Self-care maintenance</i>	<i>Self-care management</i>	<i>Self-care self- confidence</i>
Self-care management	.39*		
Self-care self- confidence	.17*	.42*	
Total scale	.63	.85*	.70*

Reprinted from Journal of Cardiac Failure, Vol 10, B. Riegel, B. Carlson, D. Moser, M. Sebern, F. Hicks, and V. Roland, "Psychometric Testing of the Self-Care of Heart Failure Index" p. 359, 2004, with permission from Elsevier, Inc.

Cognitive Impairment in Heart Failure

A comprehensive review of the literature relative to CI impairment in HF was performed utilizing the OVID database. Publications indexed in MEDLINE, CINAHL and PSYCHINFO databases were searched by keywords "cognitive impairment" and "heart failure, congestive." Approximately 175 articles were reviewed, indicating that there has been extensive publication on this topic. Articles pertinent to the study at hand will be described below.

Prevalence and Demographics

Patients diagnosed with HF, as described previously, are expected to participate in self-care, including self-care maintenance activities and self-care management activities. However, many individuals are unsuccessful at self-care, as evidenced by poor symptom recognition, poor adherence to self-care behaviors and high resource utilization. Cognitive impairment in HF may limit an individual's ability to participate in self-care activities.

Cognitive impairment is frequently discovered in individuals with HF. As described, studies have demonstrated that anywhere from 26% (Zuccala, Onder, Pedone, Carosella et al., 2001) to 77% (Putzke et al., 1997) of individuals with HF are affected with CI. The domains of cognition most frequently affected in HF and the studies they are described in are listed below in Table 6.

Table 6. Cognitive Domains Noted to be Impaired in Studies and Where Cited

<i>Domain</i>	<i>Source</i>
Memory	Almeida & Flicker, 2001 Almeida & Tamai, 2001 Callegari et al., 2002, DeShields, McDonough, Mannen & Miller, 1996 Putzke et al., 1997 Schall Petrucci, Brozena, Cararocchi & Jessup, 1989 Trojano, Incalzi, Acanfora, Picone, Mecocci & Rengo, 2003
Attention	Almeida & Flicker, 2001 Almeida & Tamai, 2001 Bornstein, Starling, Myerowitz & Haas, 1995 Trojano et al., 2003 Zuccala et al., 1997
Complex Reasoning	Bornstein et al., 1995 Putzke et al., 2000 Schall et al., 1989 Zuccala et al., 1997
Recall	Incalzi, Trojano et al., 2003 Sauve & Bennett, 1999
Learning	Callegari et al., 2002 Incalzi, Trojano et al., 2003
Psychomotor areas	Bornstein et al., 1995 Putzke et al., 1997 Putzke et al., 2000 Schall et al., 1989
Executive function	Wolfe, Worrall-Carter, Foister, Keks & Howe, 2006

When considering the cognitive domains affected by CI in HF, it is important to remember the self-care process as it relates to those specific domains. For example, self-maintenance activities involve mostly the domain of memory, as patients must remember to take their medications, monitor their vital signs and follow dietary restrictions. On the other hand, self-management activities involve more complex cognitive activities, such as perception, memory, recall, reasoning, insight and executive function. Difficulties in the cognitive domains studied thus far as well as those domains not studied, have important implications in self-management.

Many researchers have demonstrated associations between CI in HF and various demographic variables. Multiple studies have linked female gender to CI in HF (Cacciatore, et al., 1998; Zuccala, Onder, Pedone, Carosella et al., 2001; Zuccala et al., 2003; Zuccala, Marzetti et al., 2005). But, there is disagreement regarding the association of age and educational level with CI, with some (Sabatini, et al., 2002; Zuccala et al., 1997; Zuccala, Onder, Pedone, Carosella et al., 2001; Zuccala et al., 2003; and Zuccala, Marzetti et al., 2005) making associations between increasing age and prevalence of CI in individuals with HF, while others (Riegel et al., 2002) making no association between these two variables. Similar results were found when the role of educational level was considered. Decreased level of education was noted to be associated with increased prevalence of CI by Zuccala et al. (2003) and Zuccala, Marzetti et al. (2005), but not by Riegel et al. (2002). This disagreement in results will present

itself repeatedly for many variables studied. For complete descriptions of studies cited in this manuscript, including significant and negative findings, refer to Appendix A.

Measurement of Cognitive Function

When evaluating the depth of publications on the area of CI and HF, one thing is certain: a broad range of measurement tools have been used to quantify the phenomenon. Perhaps the most widely used tool to measure cognitive function in HF is the Mini-Mental Status Examination (MMSE). The MMSE is a short cognitive screening test designed to measure orientation, registration, short-term memory, attention, and calculation. Despite the fact that it is probably the most widely used cognitive screening test (Tombaugh & McIntyre, 1992), critics of the MMSE state that it is not sensitive to mild CI (Boeve et al., 2003; Kalbe et al., 2004), that it does not detect memory (Incalzi, et al., 2003) or executive function deficits (Kahokehr, Siegert & Weatherall, 2004), and that it is biased based on age (Fratiglioni et al., 1993; Launer, Dinkgreve, Jonker, Hooijer & Lindeboom, 1993; MacKenzie, Copp, Shaw & Goodwin, 1996; Mezey, Teresi, Ramsey, Mitty & Bobrowitz, 2000; Tangalos, et al., 1996), and educational level (MacKenzie et al., 1996; Olin & Zelinsky, 1991; Tangalos et al., 1996). Despite these deficits, the MMSE has acceptable sensitivity and specificity when compared to neuropsychological examination in elderly subjects (Folstein, Folstein & McHugh, 1975; MacKenzie et al., 1996).

Hodkinson's Abbreviated Mental Test (AMT) is similar to the MMSE in that it is a short screening test, consisting of only ten questions. It only assesses orientation,

attention and memory. Incalzi et al. (2003) examined the sensitivity and specificity of this test in 2808 hospitalized elderly by comparing scores on the AMT to DSM-III-R criteria for dementia. These researchers found that the AMT has acceptable sensitivity (81%) and specificity (84%) in screening for dementia in this group. Likewise, The Short Portable Mental Status Questionnaire (SPMSQ) is also a brief screening test. The SPMSQ has adequate test-retest reliability (0.82 and 0.83), but poor sensitivity (0.67), limiting its clinical use (Lezak et al, 2004).

In addition to screening tests, diagnostic tests designed to measure specific cognitive domains have been used in studies of CI in HF. One of the more frequently used tests is the Trail Making Test. The Trail Making Test is a pencil and paper test used to assess attention, orientation and visuo-spatial motor skill. The Trail Making Test is composed of two tests, Trail Making A and Trail Making B. In Trail Making A, the subject is given a sheet of paper with randomly placed numbered circles and instructed to connect the circles in sequence by a line drawn with the pencil. In Trail Making B, the subject is given a sheet with both numbered and lettered circles, and the subject is asked to connect the circles sequentially, alternating between letters and numbers. Scoring is based on time required to complete the test. Reliability of this test is said to vary between 0.6 and 0.94 depending on the group tested. Recently, attention has turned to the utilization of the Trail Making Test to measure executive function (Arbuthnott & Frank, 2000).

Various combinations of tests and comprehensive cognitive batteries have also been used in studies of CI in HF. The Cambridge Mental Disorders of the Elderly Examination (CAMDEX) is an examination that includes subject and informant interviews in addition to a 67 item instrument called the Cambridge Cognitive Examination (CAMCOG). This battery assesses orientation, language, memory, attention, praxis, calculation and perception and takes approximately 25 minutes to complete. Total score is 107, and a sensitivity of .92 and a specificity of .96 was achieved with a cut score of 80 in a diverse sample. The CAMCOG correlates well with the MMSE, and has excellent test-retest reliability (Lezak et al., 2004).

Another cognitive battery that has been used in studies of CI in HF is the Weschler Intelligence Scale for Adults (WAIS-A). The WAIS is designed to measure a variety of cognitive abilities and is composed of numerous tests that may also be administered alone. The WAIS is composed of two subscales: verbal, measuring information, comprehension, arithmetic, similarities, digit span and vocabulary, and the performance tests; digit symbol, picture completion, block design, picture arrangement and object assembly. The WAIS-A battery is said to assess domains of orientation, attention, concept formation, reasoning and constructional abilities and to be affected by age, gender and education. Despite its widespread use, use of the WAIS has come under scrutiny recently as there are no scoring adjustments made for age, gender or education (Lezak et al., 2004). For a description of these and other cognitive tests referenced in this paper, the reader is referred to Table 7 below.

Table 7. Cognitive Tests

<i>Test (domain)</i>	<i>Method</i>	<i>Time</i>	<i>Psychometrics</i>
Abbreviated Mental Test (Screening) (Incalzi et al., 2003)	10 questions assessing orientation, attention and memory.		Sensitivity 0.81 and specificity 0.84 compared to DSM-III-R criteria for dementia.
Attentional Matrices (Focused and sustained attention) (Trojano et al., 2003)	Digit cancellation task.		
Boston Diagnostic Aphasia Examination Commands Subtest, Complex Ideational Material Subtest (Verbal Functions and Language Skills) (Lezak et al., 2004)	Subject responses to semistructured interviews and conversation rated and compared to aphasic patients.	Whole battery takes 3-4 hours, subtests are generally used.	

<i>Test (domain)</i>	<i>Method</i>	<i>Time</i>	<i>Psychometrics</i>
Cambridge Exam for Mental Disorders of the Elderly (General Assessment Scale) (Lezak et al., 2004)	Observational assessment scale and CAMCOG, 67 items grouped into eight subscales, orientation, language, memory, attention, praxis, calculation, abstract thinking, and perception. Testing involves objective testing and structured interviews with patient and an informant.	CAMCOG takes 25 minutes.	CAMCOG Correlates strongly with MMSE, $r=.87$. Inter-rater reliability $r=.87$, test-retest reliability $r=.97$.
Draw a Clock (Construction and executive function) (Lezak et al., 2004)	Subjects are asked to draw a clock with hands pointing to a specific time. Various scoring scheme have been developed, some where the subject is given a blank page, others where a circle is already drawn on the page.		Inter-rater reliability for various scoring schemes = .82-.98. Sensitivity and specificity vary for scoring schemes. However, test performs universally well in differentiating Alzheimer's dementia from other forms of dementia.
Digit Span (Orientation and attention) (Lezak et al., 2004)	Seven pairs of random numbers read aloud by examiner. Subject is asked to repeat in order.		
Digit Symbol (Orientation and attention) (Lezak et al., 2004)	Subjects are asked to reproduce a symbol attached to a specific number.		Test-retest reliability =.82-.88. Effectively detected improvement in cognition in hypertensive subjects. Performance is correlated with coma duration.

<i>Test (domain)</i>	<i>Method</i>	<i>Time</i>	<i>Psychometrics</i>
Knox Cube Test (Orientation and attention) (Lezak et al., 2004)	Variant of Corsi Block Tapping, uses 4 blocks, examiner taps blocks in sequence, subject is asked to replicate in order.	Two to five minutes	Correlated significantly with Digit span ($p < .01$) in hospitalized middle and older aged males.
Letter Cancellation (Perception) (Lezak et al., 2004)	Multiple rows (usually 6) of letters (usually 52) with the cancelled letter interspersed throughout (usually 18 times per row). Subject is instructed to cancel the letter where ever it appears in the rows.	60 seconds in normal individuals	
Mini Mental Status Examination (Global cognitive function screening test) (Lezak et al., 2004)	Series of ten questions answered by the subject, a line drawing that subject is asked to replicate and sentence composition.		24 hour test-retest $r = .83$. MMSE is effective in differentiating normal subjects from subjects with cognitive deficits. Sensitivity and specificity ranges from .63-.69 and .90-.96 respectively.
Mental Status Questionnaire (Screening) (Wilson & Brass, 1973)	A series of 10 questions orientation, memory is administered verbally to the subject.	10 minutes	Correlates with rating of dementia by physical exam, $r = .82$.

<i>Test (domain)</i>	<i>Method</i>	<i>Time</i>	<i>Psychometrics</i>
Rey Auditory Verbal Learning Tests -Rey Immediate Recall -Rey Delayed Recall (Learning and retention) (Lezak et al., 2004)	A 15 word list is presented to subjects five times. The subject is asked to remember as many words as possible after each trial. This is followed by one presentation of an interference list. One immediate and one delayed (30 minutes) recall trial is then performed.	10-15 minutes to administer five trials. 20-30 afterwards, delayed trials and recognition trials add another 10 minutes.	Alternate forms test-retest reliability $r=.61$ - $.86$ for all trials (one month retest interval). For recognition and delayed recall $r = .51-.72$. Correlation with California Verbal Learning Test $r = .32$ for trial 1, $r=.33$ for trial 5, $r=.47$ for total recall and $r=.37$ for short delayed recall.
Seashore Rhythm (Perception) (Lezak et al., 2004)	Subject must identify similar and dissimilar musical beats.		Split half reliability $r=.77$ and $.62$. Brain injured subjects score poorer than normal controls, severity of injury correlates with score.
Short Portable Mental Status Questionnaire (Cognitive screening test) (Lezak et al., 2004)	Ten question, ten point test verbally administered to subject.		Test-retest reliability = $.82$ for a small group of elderly controls and $.85$ for skilled care residents. Sensitivity = $.67$, and specificity is $.96$.
Trail Making Test (Orientation and attention) (Lezak et al., 2004)	Given in two parts, Part A involves drawing lines to connect numbered circles, and Part B involves connecting numbered and lettered circles consequently and alternatively.	No longer than five minutes	Reliability reported $.60-.90$.

<i>Test (domain)</i>	<i>Method</i>	<i>Time</i>	<i>Psychometrics</i>
Weschler Intelligence Scale (Neuropsychological assessment battery (Lezak et al., 2004))	11 tests, either verbal, which are information, comprehension, arithmetic, similarities, digit span, and vocabulary, or performance, which are digit symbol, picture completion, block design, picture arrangement and object assembly.	75-120 minutes	Scores indexed based on population norms. Indexed scores tend to correlate with full scale IQ scores.
Wisconsin Card Sort (Concept formation and reasoning, executive function (Lezak et al., 2004))	60 card set with one of four symbols (triangle, star, cross or circle) printed in one of four colors (green, yellow, red and blue). Subjects are asked to sort cards according to a predetermined pattern.	Depends upon number of errors made	Poor performance on WCST correlates well with frontal lobe dysfunction.

When considering results of individual studies, it is important to note the specific cognitive test utilized, the domains assessed by each test and the strength of the relative psychometric properties. Administration length is also important, as patient fatigue may skew test results in this vulnerable population. Finally, it is also important to keep in mind the domains of cognition not assessed by the tools or battery utilized. Positive or negative findings may be explained by the choice of tools used to measure the cognitive variable.

Despite the widespread use of the MMSE to assess for CI in HF, one nursing researcher utilized a battery of neuropsychological tests including the Repeatable Battery

for the Assessment of Neuropsychological Status (RBANS) to assess attention, immediate memory and delayed memory, and the Wisconsin Card Sort Test (WCST) to assess executive function (Wolfe et al, 2006) . The RBANS will be discussed below. The WCST is a test that utilizes a 60 card set upon which is printed one of four symbols (triangle, star, cross or circle), in one of four colors (green, yellow, red and blue) and one of four quantities (one, two, three or four). Subjects are asked to sort the cards according to a predetermined pattern (by color first, followed by shape then number). The examiner informs the subject when an error in sorting has been made. Readjustments are then made by the subject, reflecting the assessment, reassessment and readjustment processes known to be present in executive function. This test is scored based on the number of correct sorts (categories completed), or on the number of times the subject continues to sort incorrectly (perseverative errors). (Lezak et al., 2004). The investigators in this study determined that significant deficits were present in memory and executive function in HF patients, but there was no correlation between severity of HF as measured by ejection fraction (EF) and cognitive performance.

As previously described, CI is a widely studied phenomenon in the literature. However, there is little consistency in results or in measurement methodology. Short screening tests that lack sensitivity for mild cognitive impairment, or that do not measure domains of cognition known to be impaired in HF are generally used. On the other hand, other studies have used lengthy comprehensive diagnostic batteries. These batteries, some of which took three to four hours to complete, may have spurious results secondary

to fatigue. In order to have a true understanding of the effect of CI in HF, it is vitally important that cognitive tests accurately measure the intended domains of cognition. A brief description of the Repeatable Battery for Neuropsychological Status (RBANS), the Controlled Oral Word Association Test (COWAT) and the Anosognosia Questionnaire-Dementia (AQ-D) followed by psychometric performance of each test will follow.

Repeatable Battery for the Assessment of Neuropsychological Status

The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) (Randolph, 1998) was originally developed to serve as a screening tool for dementia in the elderly. It has however, gained widespread use as a general screening battery. The RBANS is a 12 test battery that consists of five subscales: immediate memory, delayed memory, language, attention and visuospatial/constructional. Each subscale as well as the total scale, are scored on a standardized scoring scale with mean scores of 100 and standard deviation of 15. The complete 12 test battery can be administered in 30 minutes. The RBANS is said to be particularly useful in situations where a longer, comprehensive battery is not possible (Lezak et al, 2004). Please see Appendix C for a copy of the RBANS.

Normative values

Normative values were immediately published for age ranges from 20 to 89 (Lezak et al, 2004), and subsequently, normative values for older adults (mean age 73 years) have been published (Patton, Duff, Schoenberg, Mold, Scott & Adams, 2006). Additional normative values have been published for age and education (Duff, Patton,

Schoenberg, Mold, Scott & Adams, 2003; Gontkovsky, Mold & Beatty, 2002), gender and education (Beatty, Mold & Gontkovsky, 2003), race (Patton, et al., 2003), and in schizophrenic patients (Wilk, et al., 2003). Other investigators have developed normative change indexes to be used for predicting change over one (Duff, Schoenberg, Patton, Paulsen, Bayless et al, 2005; Patton, et al., 2005) and two years (Duff, et al., 2004). Since the RBANS is designed to be repeated over different intervals, it has been found to have no real practice effect over one year (Duff, Beglinger, Schoenberg, Patton, Mold, Scott et al, 2005).

Multiple studies have described the reliability and validity of the RBANS. These have included test/retest reliability, internal consistency reliability, construct validity, criterion validity, concurrent validity, discriminant validity and predictive validity. Some of these studies will be briefly described below. For a complete list of psychometric studies of the RBANS, please see Appendix D, Psychometric properties of the RBANS.

Reliability

Many researchers have assessed test-retest reliability of the RBANS. Duff, Beglinger et al. (2005) assessed the one-year test-retest reliability for the RBANS total and subscale scores. In this sample of 455 elderly community based participants, total scale test-retest reliability was adequate ($r=.82$) as were the immediate memory ($r=.70$), and delayed memory ($r=.77$) subscales. The language ($r=.58$), attention ($r=.58$) and visuospatial/constructional ($r=.62$) fared less well, however. Similar results were found in a study by Gold, Queern, Iannone & Buchanan (1999) in schizophrenic patients. Total

scale ($r=.84$), immediate memory ($r=.72$), and attention ($r=.91$) subscales showed relative consistency over the 12 week study period, while the visuospatial/constructional ($r=.68$), delayed memory ($r=.64$), and language ($r=.51$) subscales did not. Finally, Wilk et al. (2002) measured six week test-retest reliability in 181 schizophrenic patients and 181 relative controls with similar results. Total scale scores were adequate for the schizophrenic and control groups ($r=.84$ and $.78$ respectively), but specific subscales did not exhibit stability, such as the language subscale ($r=.54$) for the schizophrenic group and the immediate memory ($r=.55$), visuospatial/constructional ($r=.53$), language ($r=.38$) and delayed memory ($r=.57$) for the control group.

Another measure of reliability, internal consistency, was also measured for the RBANS. Gold et al. (1999) also evaluated the internal consistency of the RBANS, and found it to be quite high, Cronbach's $\alpha=.88$ in a group of schizophrenic patients. McKay, Casey, Wertheimer, and Fichtenberg, (2007) measured the internal consistency of the RBANS in a sample of 57 patients with moderate to severe brain injury. Total scale alpha was also quite high ($\alpha=.84$), but subscales performed less well, with attention $\alpha=.16$, language $\alpha=.32$, immediate memory $\alpha=.75$, visuospatial/constructional $\alpha=.76$, and delayed memory $\alpha=.77$. However, the investigators hypothesized that alpha scores for the subscales attention and language would be low, exemplifying the variability of these domains relative to the study sample. As noted, this hypothesis was supported.

Validity

The RBANS has also undergone validity testing with a variety of methods in a variety of populations. Construct validity of the RBANS was assessed in community dwelling elders (Duff, Langbehn et al., 2006) and in ischemic stroke patients (Wilde, 2006). Duff, Langbehn et al. (2006) studied construct validity of the RBANS in 824 elderly persons living in the community. Confirmatory factor analysis was performed for both one and five factor solutions, but neither solution was supported. Exploratory factor analysis supported a two factor solution with Eigenvalues of 4.09 and 1.29. The first factor contained story memory, list learning, list recognition, list recall and story recall tests. The second factor contained coding, figure copy, figure recall and line orientation tests. Exploratory factor analysis revealed similar results in the study by Wilde (2006), where a two factor solution was also uncovered. The first factor, with an Eigenvalue of 5.33 was a language/verbal memory factor, and the second factor, with an Eigenvalue of 1.98 was a visuospatial/visual memory factor. These two factors correlate with the two factors demonstrated by Duff, Langebehn et al. The two factor solutions delineated in each of these studies perhaps speaks less to the underlying validity of the scale, but rather to the highly inter-related cognitive domains assessed.

Like construct validity, multiple studies have assessed criterion validity for both the total scale as well as the subscale scores. Ryder, McSwan, Scott, Bharucha and Beatty (2002) correlated the RBANS total score with MMSE scores ($r=.756$) in 27 patients with Parkinson's disease. Similar results were found in a study by Hobart,

Goldberg, Bartko, and Gold (1999). In this study, 150 participants with various psychiatric disorders were examined. Total RBANS scores correlated with Weschler Adult Intelligence Scale ($r=.75$). The results of these studies indicate the RBANS performs relatively well against other general measures of cognitive function.

Generally, RBANS subscales correlate well with other cognitive tests designed to measure similar constructs, although some of these correlations, while significant, are weak. McKay, et al. (2007) assessed subscale scores against various cognitive tests. The RBANS subscales performed well, with correlations ranging from $-.317$ to $.827$.

Gontkovsky, Hillary and Scott (2002) correlated the RBANS figure copy to the Rey Complex Figure Test ($r=.76$, $p<.001$) and the RBANS figure recall to the Rey Complex Figure Test Delayed Recall ($r=.65$, $p<.001$). Similarly, RBANS picture naming correlated well with the Boston Naming Test ($r=.71$, $p<.001$) and RBANS semantic fluency correlated well with the Controlled Oral Word Association Test ($r=.74$, $p<.001$). For complete listing of subscales studied with significant correlations, please see Appendix D.

The RBANS has been used to discriminate cognitive performance in a variety of populations, including the elderly (Randolph, Tierney, Mohr & Chase, 1998), those with schizophrenia (Gold et al, 1999), those with Alzheimer's disease (Beatty, et al., 2002; Randolph et al., 1998), those with Huntington's disease (Randolph et al., 1998) and those with multiple sclerosis (Beatty, 2004) from normal controls or from other diseases. Finally, Larson, Kirschner, Bode, Heinemann and Goodman (2005) utilized the RBANS

to predict functional recovery in stroke patients. Subscale RBANS scores correlated with scores on the Cognitive Factor of the Functional Independence Measure (attention $r=.48$, immediate memory $r=.61$, delayed memory $r=.63$, visuospatial/constructional $r=.63$ and total scale $r=.72$).

Although the RBANS total scale performs well against similar global cognitive instruments, studies have demonstrated a large amount of variability in validity of the individual subscales. Multiple studies have attempted to demonstrate validity against several criterion measures in many different populations. It is difficult to interpret results, as a wide variety of tests measuring memory, attention, language and constructional skills were used, and none of the subscales performed consistently better than any other. Similarly, few studies were performed with normal samples. Despite the fact that this instrument was originally designed to assess for dementia, criterion testing should be performed in normal as well as impaired populations.

Despite the limitations outlined above, the RBANS has become a widely used instrument for general cognitive assessment. The length of the RBANS and its relative completeness in regards to cognitive domains add to the utility of this scale. The relative completeness of cognitive domains assessed as well as the length of administration make the utilization of this tool particularly appealing in the HF population. It has similarly been utilized in the HF population, where it detected impairment in memory and visuospatial/construction domains.

Controlled Oral Word Association

The Controlled Oral Word Association (COWAT) is a test of verbal fluency that consists of three short trials. In each of these three trials, the subject is instructed to say as many words as possible beginning with a specific letter, such as “C” or “D,” in one minute. Proper nouns and variations of the same word (such as cat and cats) are not considered towards the total word count. The score is the total number of unique words iterated during the three one minute trials. This test was first called the Verbal Associative Fluency Test and later called the Controlled Word Association Test. However, it is often referred to as the F-A-S Test, as these are the letters most frequently used in trials (Lezak, et al., 2004).

As previously stated, executive functions are those processes that enable human organisms to behave in an independent, purposeful and self-directed manner. Executive function forms the basis for socially acceptable behavior and is evident in the human ability to initiate action, set goals, organize behavior to meet goals, perform activities to meet goals and monitor and correct behavior if necessary (Lezak, et al., 2004). In fact, executive function has been described as a metacognitive function, an integrated activity that involves many cognitive skills (Katz & Hartman-Maier, 1997). Processing of these cognitive skills have long been attributed to the frontal lobes of the brain (Kolb and Wishaw, 2003), and much of the early work on the COWAT and similar tests has focused on the association between verbal fluency and frontal lobe dysfunction, specifically left prefrontal function (Ruff, Light, Parker & Levin, 1997).

Verbal fluency can be described as an executive function based on the metacognitive nature of its performance. Verbal fluency requires interrelationships between immediate attention, verbal memory, word knowledge, declarative memory, and working memory (Ross, Calhoun, Cox, Wenner, Kono & Pleasant, 2007; Ruff, et al., 1997). Specifically, the COWAT is thought to assess executive function by measuring the ability of the subject to continuously monitor (Ruff, et al., 1997) or regulate (Ross, et al., 2007) processing between these cognitive domains. The utilization of specific letters further complicates the process by restricting the condition under which the test conditions are performed (Bell-McGinty, Podell, Franzen, Baird & Williams, 2002; Sumerall, Timmons, James, Ewing & Delbert, 1997). Moreover, in the previously discussed study by Pineda and Merchan (2003), five factors emerged in an exploratory factor analysis of executive function, including sustained attention, inhibitory control and verbal fluency, cognitive domains assessed by the COWAT.

Normative values

As previously stated, scoring for the COWAT represents the total number of words correctly stated during the three one minute trials. Raw word scores are adjusted for age, gender and educational level with correction values developed by Benton, Hamsher and Sivan in 1994 and published in Lezak, et al. (2004). Normative values, including means and standard deviations for various age groups and educational levels for the COWAT were subsequently published by Spreen and Straus (1998). However, normative values did not include the very elderly and therefore, Sumerall, et al. (1997)

published means for individuals 70 to 95 years of age. Other studies have examined the influence of age and education on COWAT scores, and normative values for these characteristics have also been published utilizing large samples of cognitively normal, community dwelling individuals (Ruff, Light, Parker & Levin, 1996; Tombaugh, Kozak & Rees, 1999). The effect of age and gender on COWAT scores was examined by Yeudall, Fromm, Reddon and Stefanyk (1986). Several investigators have examined the influence of race on COWAT scores (Gladsjo, et al., 1999; Johnson-Selfridge, Zalewski & Aboudarham, 1998). In a study of 600 male veterans, Gladsjo, et al. (1999) determined that Hispanic participants performed the poorest, followed by African American participants and finally, Caucasian participants. Normative values for age, educational level and ethnicity were then published by Gladsjo, et al. (1999). Finally, investigators have developed normative values for various clinical groups, including high school athletes (Barr, 2003) and those who have experienced traumatic brain injury (Iverson, Franzen & Lovell, 1999).

Reliability

Multiple studies have assessed the reliability of the COWAT. Test-retest reliability has been documented in normal control groups at various time intervals. Basso, Bornstein and Lang (1999) administered the Wisconsin Card Sort, the Ruff Figural Fluency Test, Verbal Concept Attainment Test, the Trail Making Test and the F-A-S verbal fluency test at baseline and again 12 months later to determine the effect of practice on performance of these tests. Eighty two community based, healthy male

volunteers without a history of neurological disease or injury, were administered the tests at baseline, and again to 50 of the original sample. Total word scores for the F-A-S test were stable over the twelve months ($F=.48$, $p=ns$), unlike the Wisconsin Card Sort, the Verbal Concept Attainment Test and the Ruff Figural Fluency Test, which exhibited significant practice effect.

In another study, Ruff, et al. (1996) set out to examine the reliability of the COWAT. In this study, 360 community based volunteers aged 16-70 years, were administered the COWAT at baseline, using the letters “c,” “f” and “l.” A second group of 120 subjects randomly selected from the pool of original subjects was administered the COWAT a second time, using the letters “p,” “r” and “w.” The repeat testing was performed six months after the initial testing. Test-retest reliability for the group was high, $R=.74$, $p<.001$).

Still other studies utilized healthy, younger samples. In a small study, Barr (2003) administered the COWAT to 60 male and 40 female high school athletes at baseline and to 48 of the original subjects eight weeks later. Test-retest reliability for total word score was .680 (p value not given). However, Ross, et al. (2007) administered the COWAT to 55 healthy undergraduate college students at baseline and again 44 days later. Test-retest reliability for this sample was higher as measured by intercorrelation coefficients ($r=.84$, $p<.001$). Finally, Kneebone, Andrew, Baker and Knight (1998) administered the COWAT to normal control subjects at baseline and following seven days. Test-retest reliability for this sample of 24 normal controls was high, $r=.84$ ($p<.01$) at seven days. It

is important to note that the sample of high school students demonstrated poorer stability in COWAT scores over time, which may be function of the age of the sample and not of the test itself. Similar variability in other cognitive tests scores has been identified with other samples in this age metric (Barr, 2003).

Internal consistency reliability was assessed by Ruff, et al. (1996), who administered the COWAT to 360 community based volunteers. Participants were between 16 and 70 years of age with seven to twenty-two years of education. Anyone with a history of neurological dysfunction, hospitalization for psychiatric illness or chronic substance abuse was excluded from participation. The word scores from the three trials separately and the total word score were entered into analysis. Results indicated that the alpha was quite high, at .83, indicating adequate internal consistency.

All things considered, the COWAT is a stable test as measured over a variety of intervals in nonclinical samples. It also demonstrates strong internal consistency. Granted, the number of studies assessing the reliability of this test is small, and further studies should be undertaken with clinical samples at various time intervals.

Validity

Establishing the validity of the COWAT as a measure of executive function has been the aim of numerous recent studies. As previously stated, the early studies focused on establishing the relationship between verbal fluency and frontal lobe lesions. One such study was performed by Benton (1968). In this study, 25 subjects were placed in one of three groups: those with right frontal lobe lesions (four men and four women),

those with left frontal lobe lesions (six men, four women) and those with lesions of both frontal lobes (six men, one woman). The Verbal Associative Fluency test was given, utilizing the letters “f,” “a” and “s,” in addition to tests of associative learning, construction, design copy, orientation and interpretation. Participants with right sided lesions had significantly better verbal fluency than those with left sided lesions ($p < .1$) and those with bilateral lesions ($p < .05$). On the other hand, participants with left sided lesions did not perform better than those with bilateral lesions. It would appear that left sided organic brain lesions are associated with poorer verbal fluency performance.

A similar study was performed by Perret (1974). This study also examined the effect of frontal brain lesions on verbal fluency. In this study, 118 right handed patients who were undergoing brain surgery for lesions in various cerebral locations were examined with the Modified Stroop Test and a verbal fluency test. Administration of the verbal fluency test was different from that described above. In this iteration, the participants were asked to state as many words as they could beginning with the letter “s” in five minutes for the first trial. For the second trial, participants were asked to state as many four letter words that they could starting with the letter “b.” Performance on the verbal fluency test discriminated those participants with frontal lesions from those with temporal and parietal lesions, as well as discriminating those participants with right sided lesions from those with left sided lesions.

Criterion validity of the COWAT as a measure of executive function has been assessed in numerous studies. When examining the results of these studies, it is

important, however, to consider the multifaceted nature of executive function. In order to reasonably assess the COWAT's criterion validity, criterion tests must measure the same or similar construct of the metaparadigm cognitive function, and not be affected by other constructs not measured by the COWAT. As discussed, the COWAT assesses executive function by virtue of verbal fluency, which requires cognitive domains of immediate attention, verbal memory, word knowledge, declarative memory, and working memory to function in a cohesive manner (Ross, et al., 2007; Ruff, et al., 1997). Stated more specifically, criterion tests should focus on the regulatory and monitoring function of executive function in order to accurately assess the validity of the COWAT.

One of the tests frequently used to measure validity of the COWAT is the Trail Making Test (TMT). As previously discussed, the Trail Making Test is a pencil and paper test consisting of two parts where the examinee is asked to connect 25 numbered and lettered circles with a pencil line without lifting the pencil off the paper. For the first part, TMT part A, the examinee is asked to connect 25 numbered circles with a pencil line. For the second part, TMT part B, the examinee is asked to connect numbered and lettered circles with a pencil line by alternating between numbers and circles, for example, a-1-b-2-c-3-d-4, and so on. Scoring is based on how long it takes to complete the task correctly. Although this test was originally thought to measure orientation, attention and psychomotor speed, recent attention has turned to its ability to measure executive function (Lezak, et al., 2004). The Trail Making Test is thought to assess executive function by measuring the ability of the individual to alternate between tasks

(as in the TMT part B), thereby measuring the control and inhibitory aspects of executive function. In a study performed by Arbuthnott and Frank (2000), 34 college students were administered the TMT and set switching tasks. In this study, performance on alternating tasks was correlated with TMT part B scores, leading the investigators to conclude that TMT part B scores assess attentional control. However, it should be mentioned that TMT tests also assess psychomotor speed, and that scores on this test may be impacted in specific groups or by specific health conditions.

That being said, multiple studies have utilized the TMT part B test to assess the validity of the COWAT. One of these studies utilized a total of 50 community based participants, six community dwelling elderly, nine skilled nursing facility residents and thirty-five individuals referred for neuropsychological examination (Bell-McGinty, et al., 2002). The mean age of the participants was 74.5 years (range = 63-89), with 12.4 years of education (range = 3-20). In order to obtain a wide range of individuals for study, individuals with psychiatric or medical conditions were included in recruitment. Controlled Oral Word Association Test scores correlated fairly well with TMT part B scores ($r = -.64$, $p < .001$). Similar results were found in a study by McGovern (2007), using a sample of 81 participants with dementia ($n = 30$), sleep apnea ($n = 21$) and normal controls ($n = 30$). In this study, the mean age of participants was younger (69, range 44-85), and evenly divided between males and females (41 females, 40 males). Controlled Oral Word Association Tests correlated with TMT part B tests ($r = .59$, $p < .005$) for the sample. On the other hand, weaker but significant correlations were found between the

COWAT and TMT part B tests in a study by Chaytor, Schmitter, Edgecombe and Burr (2006), where 46 adults referred for neuropsychological testing were administered these two tests. The mean age of participants was 40.87 years of age (range 15-75), and had a clinical diagnosis of traumatic brain injury (26.1%), epilepsy (34.8%), or other disorders such as multiple sclerosis, tumor, stroke or arteriovenous malformation (39.1%). For this sample, TMT part B scores correlated significantly but weakly with COWAT scores ($r=.38$, $p<.05$). Certainly, the lower correlation in this study can be explained by the diverse nature of this sample, which includes those who may have significant motor function impairment.

Another study assessed criterion validity of the COWAT by comparing it to the Stroop Test. The Stroop Test is a measure of attention and orientation and requires the examinee to state the name of a color depicted on a card in one of many ways (Lezak, et al., 2004). In this study, Perret (1974) utilized part D, part W and part C of the Stroop test and the COWAT to discriminate location of brain lesion in 118 subjects who were about to undergo brain surgery. The format of the Stroop Test used involved naming the color of 24 dots printed in six rows of four columns on a card (part D), naming the color as a written word arranged similarly on a card (part W) and finally, naming the color of letters forming a color name that is not the same as the color of the letters (part C), for example, the color blue spelled out in red letters. Total score is the time required to name the 24 items correctly. It is believed that the Stroop Test measures the control and flexibility aspects of executive function (Rossi, Daneluzzo, Mattei, Bustini, Casacchia &

Stratta, 1997). In this study, Perret (1974) stratified the sample by location of brain lesion, and all three parts of the Stroop correlated well with the COWAT, but larger correlations were seen in the left hemisphere groups, and in part W and C as noted in table 8 below:

Table 8. Correlations of COWAT to Stroop Test by Brain Lesion Location

	<u>Right</u>			<u>Left</u>		
	Frontal	Temporal	Posterior	Frontal	Temporal	Posterior
Part D	-.46/.02*	NS	NS	-.48/.02*	-.56/.04*	-.53/.02*
Part W	-.53/.006*	NS	NS	-.70/.0003*	-.72/.004*	-.61/.008*
Part C	-.54/.005*	NS	NS	-.72/.0002*	-.61/.02*	-.63/.005*

* r value/p value

Reprinted from Neuropsychologia, Vol 12, E. Perret, "The Left Frontal Lobe of Man and the Suppression of Habitual Responses in Verbal Categorical Behaviour" p. 326, 1974, with permission from Elsevier, Inc.

As noted, the correlations between the COWAT and the Stroop test are strongest in the left frontal group, particularly for part W and part C, which favorably represents the executive function processes assessed by the COWAT.

The validity of the COWAT as measured against functional status was assessed in a study by Bell-McGinty, et al. (2002). In this previously described study, six elderly participants living in the community, nine residents of skilled nursing facilities, and 35 participants who were referred for neuropsychological testing were administered the COWAT, other tests of executive function, the Dementia Rating Scale and the Independent Living Scale. The Independent Living Scale (ILS) is a 75 item scale

designed to measure the ability of an individual to live independently. It consists of five subscales: memory/orientation, managing money, managing home and transportation, health and safety and social adjustment. Higher scores on the ILS indicate better ability to live independently. Scores on the COWAT correlated with full scale scores for the ILS ($r=.53$, $p<.001$), and the money ($r=.49$, $p<.001$), home ($r=.57$, $p<.001$) and health ($r=.48$, $p<.001$) subscales. Better performance on the COWAT correlated with improved functional ability.

Concurrent validity of the COWAT has likewise been measured in a variety of studies. As previously described, Benton (1968) found that participants with right sided brain lesions scored significantly better on the COWAT than those with left sided ($p<.1$) and those with bilateral ($p<.05$) brain lesions. Similar results were found by Perrett (1974), where verbal fluency discriminated participants with frontal lesions from those with temporal and parietal lesions and those with left hemispheric lesions from those with right hemispheric lesions.

In yet another previously described study, McGovern (2007) found that the COWAT successfully discriminated normal control subjects from those with dementia [$F(2, 78)=18.95$, $p<.05$]. Subjects with mild traumatic brain injury were compared to normal controls in a study by Brooks, Fos, Greve and Hammond (1999). In this study, 11 right handed adult participants with mild traumatic brain injury were administered the COWAT, TMT part A and B, the Paced Auditory Serial Task, the Weschler Intelligence Scale for Children –Revised: Mazes subtest and the Boston Naming Test. The same

battery of tests were also administered to 13 normal controls. The study group scored significantly lower than the control group on the TMT part A and B, the COWAT and the Paced Auditory Serial Addition Task.

Finally, 32 normal college students were administered the COWAT in a study by Hildebrand (1997). The sample was mostly female (18) and young (mean age 23.23, range 17-40), and mostly Caucasian (88%). Participants were all full time college students with a course load of 12 academic hours or more. Scores on the COWAT compared favorably with grade point average, accounting for 24% of the variance ($r=.4949$, $df(29)$, $p=.0046$).

The Controlled Oral Word Association Test was used to predict functional outcome in a study by Crean (2003). In this study, 163 participants with mild traumatic brain injury and 20 normal controls were given the COWAT at baseline. Of those 163 participants, 75 patients completed the 12 month study. Participants were divided into two work statuses, full duty and limited duty, based on their ability to perform duties necessary for job performance at 12 months after injury. Baseline scores on the COWAT were significantly lower for the full duty group as compared to the normal control group ($p=.004$) as well as for the limited duty group as compared to the normal control group ($p=.004$). Discriminant function analysis revealed that baseline COWAT scores predicted work status 12 months after injury. For a graphic depiction of the psychometric properties of the COWAT, please see Table 9 below.

Table 9. Psychometric Properties of the Controlled Oral Word Association Test

<i>Type</i>	<i>Sample</i>	<i>Result</i>	<i>Author</i>
Test-retest reliability	50 participants undergoing coronary artery bypass grafting and 24 normal controls	7 day test-retest reliability for normal controls = .84, $p < .01$	Kneebone, Andrew, Baker & Knight, 1998
Test-retest reliability	50 community based male volunteers without history of neurological disease or injury	F-A-S verbal fluency scores did not change over the one year study interval ($F = .48$)	Basso, Bornstein & Lang, 1999
Test-retest reliability	48 high school athletes	56 day test-retest reliability = .680 for entire sample,	Barr, 2003
Test-retest reliability	120 participants out of original sample of 360 normal volunteers ages 16-70 years	Six month test-retest reliability was significant ($r = .74$, $p < .001$)	Ruff, Light, Parker & Levin, 1996
Test-retest reliability	53 healthy undergraduate students	Test-retest reliability of total word score as measured by intercorrelation coefficients $r = .84$, $p < .001$ after 45 days.	Ross, Calhoun, Cox, Wenner, Kono & Pleasant, 2007
Internal consistency reliability	360 community based volunteers, aged 16-70	Internal consistency computed by comparing number of words iterated for each of three letters as individual items along with the total score as another item, $r = .83$	Ruff, Light, Parker & Levin, 1996

<i>Type</i>	<i>Sample</i>	<i>Result</i>	<i>Author</i>
Criterion validity	50 study participants, 6 community dwelling elderly, 9 nursing home residents, and 35 individuals referred for neuropsychological evaluation	COWAT total scores correlated with Trail Making part B scores ($r = -.64$, $p < .001$), with Manual Postures ($r = -.48$, $p < .001$) and with the Initiation/Perseveration Index of the Dementia Rating Scale ($r = .60$, $p < .001$). COWAT total scores also correlated with full scale scores for the Independent Living Scale ($r = .53$, $p < .001$) and with the Money ($r = .49$, $p < .001$), Home ($r = .57$, $p < .001$) and Health ($r = .48$, $p < .001$) subscales	Bell-McGinty, Podell, Franzen, Baird & Williams, 2002
Criterion validity	46 adults referred for neuropsychological testing	COWAT total scores correlated with Trail Making Test part B ($r = .38$, $p < .01$), Trail Making Test B-A ($r = .32$, $p < .05$), Stroop Color/Word naming trial ($r = .36$, $p < .05$) and Wisconsin Card Sort ($r = .33$, $p < .05$)	Chaytor, Schmitter-Edgecombe & Burr, 2006
Criterion validity	81 participants, 30 with dementia, 21 with sleep apnea and 30 normal control	COWAT correlated with Trail Making Test, $r = .59$, $p < .05$	McGovern, 2007

<i>Type</i>	<i>Sample</i>	<i>Result</i>	<i>Author</i>
Criterion validity	118 right handed patients with brain lesions undergoing surgery	Verbal fluency scores correlated with Stroop-Test scores for all left hemispheric patient subgroups, and right frontal subgroup. Stroop part D: left frontal $r=-.48$, $p=.02$; left temporal $r=-.56$, $p=.04$; left posterior $r=-.53$, $p=.02$; right frontal $r=-.46$, $p=.02$. Stroop part W: left frontal $r=-.70$, $p=.0003$; left temporal $r=-.72$, $p=.004$; left posterior $r=.61$, $p=.008$; right frontal $r=-.53$, $p=.006$. Stroop part C: left frontal $r=-.72$, $p=.0002$, left temporal $r=-.61$, $p=.02$; left posterior $r=-.63$, $p=.005$; right frontal $r=-.54$, $p=.005$.	Perret, 1974
Concurrent validity	81 participants, 30 with dementia, 21 with sleep apnea and 30 normal controls	COWAT separated normal controls from participants with dementia $F(2, 78) = 18.95$, $p < 0.05$.	McGovern, 2007
Concurrent validity	32 full time college students	COWAT total scores correlated with academic success as measured by grade point average.	Hildebrand, 1997

<i>Type</i>	<i>Sample</i>	<i>Result</i>	<i>Author</i>
Concurrent validity	118 right handed patients with brain lesions undergoing surgery	Verbal fluency performance discriminated patients with frontal lesions from patients with temporal and posterior lesions, and patients with left hemispheric lesions from those with right hemispheric lesions.	Perret, 1974
Concurrent validity	25 participants with lesions of the right frontal lobe (8), left frontal lobe (10), or both frontal lobes (7)	Participants with right sided lesions had significantly better verbal fluency than those with left sided lesions ($p < .1$) and those with bilateral lesions ($p < .05$). Those with left sided lesions did not perform better than those with bilateral lesions.	Benton, 1968
Concurrent validity	11 right handed adults with mild traumatic brain injury and 13 right handed controls	Participants with mild traumatic brain injury scored significantly worse on COWAT compared to controls, $t=3.34$, $p < .01$.	Brooks, Fos, Greve, & Hammond, 1999
Predictive validity	163 mild traumatic brain injured patients and 20 normal controls	COWAT scores at baseline predicted work status 12 months later.	Crean, 2003

To be sure, the metacognitive nature of executive function makes it very difficult to accurately assess by means of a single test. The nature of executive function assessment is eloquently described by Bryan and Luszcz as almost impossible with a single test “because an essential element of the theoretical construct of executive function, and therefore tests which measure it, is that it (executive function) entails the simultaneous management of a variety of different cognitive functions” (2000, p. 42). Although not initially used as a measure of executive function, the COWAT has become an acceptable test to measure specific aspects of executive function. It is reliable, not prone to practice effects and valid in normal as well as clinical groups. The COWAT is certainly applicable for use in this study, as the monitoring and regulatory functions of executive function are particularly applicable to self-care in HF.

Anosognosia Questionnaire-Dementia

The Anosognosia Questionnaire-Dementia was developed by Migliorelli, et al., (1995) to measure anosognosia in Alzheimer’s disease. This tool is a 30 item questionnaire designed to be read and answered by the patient. Patients are asked to answer questions relating to their memory, orientation, executive function, psychomotor skills and mood by circling the appropriate answer on the questionnaire. Each question is answered on a four point rating scale, the answers being never (no points), sometimes (one point), usually (two points), or always (three points). A second form of the questionnaire is given to a caregiver or relative who is blinded to the patient responses. This caregiver form contains the same questions as the patient form except that the

questions are in the third instead of the first person. The caregiver or relative is asked to answer the questions on the same four- point scale. Total scores are calculated for each questionnaire by adding the score for each question. Total scores from the patient form are subtracted from the caregiver form to give a final score, and the higher the number, the greater the anosognosia (the caregiver rated the patient as more impaired than the patient thought he or she was). In a study of 103 patients with Alzheimers's Disease, the mean score for the tool was 14, therefore scores of less than 14 are considered normal. Scores greater than one standard deviation above the mean (or 32) are considered abnormal and consistent with anosognosia (Migliorelli et al., 1995; Starkstein, Sabe, Cuerva, Kuzis, & Leiguarda, 1997). The AQ-D is a short, easy questionnaire and does not place undue burden on the patient. The reading level is grade 8.6 for the patient version and 9.1 for the caregiver portion. The questionnaire may be read aloud to the visually impaired. Please refer to Appendix E for a copy of the patient and caregiver forms of the AQ-D.

Reliability

Several studies have examined the psychometric properties of the AQ-D. Migliorelli et al. (1995) examined the reliability of the tool in ten patients and their caregivers. The questionnaire was administered at baseline and again one month later. Test-retest reliability in this group proved to be very high, with patients (Form A) $r=.90$ ($p=.0001$) and caregivers (Form B) $r=.91$ ($p=.0001$). Internal consistency of the AQ-D

was also evaluated by Migliorelli et al. (1995). The AQ-D performed well with patient $\alpha = .91$ and caregiver α of .90.

Validity

Validity of the AQ-D has been assessed by many methods. Construct validity of the AQ-D was examined by Starkstein, Jorge, Mizrahi and Robinson (2006) in 750 participants with Alzheimer's Disease and 32 health controls. Four factors emerged from principle component analysis. These four factors were instrumental activities of daily living (Eigenvalue 9.05, variance =30%), basic activities of daily living (Eigenvalue 1.54, variance =5), depression (Eigenvalue 1.65, variance 6%) and disinhibition (Eigenvalue 1.22, variance 4%).

Starkstein et al. (2006) evaluated criterion validity of the AQ-D. In this study of 750 patients with Alzheimers disease, AQ-D scores correlated well with MMSE scores in multiple regression analysis ($R^2=.34$, $p<.0001$). On the other hand, divergent validity of the AQ-D was measured by Chemerinski, Petracca, Teson, Sabe, Leiguarda and Starkstein (1998). The investigators evaluated 196 patients with probable Alzheimer's dementia with the AQ-D, the Overt Aggression Scale and the Irritability Scale. There was no significant correlation between scales, suggesting that each scale measures distinct phenomenon.

Perhaps the largest number of psychometric studies evaluated the performance of the AQ-D against neuropsychologist examination. Concurrent validity of the AQ-D was assessed in a sample of ten patients who were evaluated by a neuropsychologist for

presence of anosognosia (Migliorelli, et al., 1995). Patients felt to exhibit signs of anosognosia had significantly higher AQ-D scores than those who did not exhibit such signs ($t=7.5$, $df=18$, $p<.0001$). Likewise, Starkstein et al. (2006) assessed concurrent validity of the AQ-D in 104 patients with Alzheimer's disease. Patients judged to have a clinical diagnosis of anosognosia as made by a neuropsychologist had significantly higher AQ-D scores on all four factors than those who did not have anosognosia.

In a very interesting study, functional neuroimaging was used to correlate changes in cerebral blood flow to the presence of anosognosia. Starkstein, et al. (1995) measured cerebral blood flow by single photon emission technetium Tc 99m hexmethylpropylene-amine oxime computerized tomography. Twelve participants with Alzheimer's dementia and anosognosia were matched to twelve participants with Alzheimer's dementia without anosognosia by age, duration of illness and level of cognitive decline. Three way analysis of variance showed that patients with anosognosia showed decreases in cerebral blood flow in right hemispheric frontal inferior and frontal superior areas of the brain. It is felt that anosognosia represents a frontal lobe process (Kolb & Whishaw, 2003). This study, while small, provides an important argument for an anatomical basis for this lack of self-awareness.

To be sure, there is a limited number of studies evaluating the psychometric performance of the AQ-D. Many of these studies were performed with a relatively small sample and most, if not all, were performed with samples consisting of patients with Alzheimer's disease or dementia. However, for those studies performed, the tool

consistently performed well, particularly against neuropsychologist examination. It is reliable and valid test for anosognosia. Please see Table 10 below for graphic depiction of psychometric properties of the AQ-D.

Table 10. Psychometric Properties of the AQ-D

<i>Type</i>	<i>Sample</i>	<i>Result</i>	<i>Author</i>
Test-retest reliability (30 day)	10 patients with Alzheimer's disease	Patient $r=.90$ Caregiver $r=.91$	Migliorelli et al. (1995)
Internal consistency reliability	10 patients with Alzheimer's disease	Patient $\alpha=.91$ Caregiver $\alpha=.90$	Migliorelli et al. (1995)
Construct validity via principle component analysis	750 patients with Alzheimer's disease and 32 healthy controls	Four factor solution, instrumental activities of daily living (Eigenvalue 9.05), basic activities of daily living (Eigenvalue 1.54), depression (Eigenvalue 1.65) and disinhibition (Eigenvalue 1.22)	Starkstein et al. (2006)
Discriminant validity	196 patients with probable Alzheimer's dementia	No correlation between AQ-D scores, Overt Aggression Scale scores and Irritability Scale scores	Chemerinski et al. (1998)
Criterion validity	750 patients with Alzheimer's disease	MMSE scores correlated well with AQ-D scores in multiple regression ($R^2=.34$)	Starkstein et al. (2006)

<i>Type</i>	<i>Sample</i>	<i>Result</i>	<i>Author</i>
Concurrent validity	10 patients with Alzheimers disease	AQ-D scores significantly differed ($t=7.5$, df 18, $p<.0001$) between patients with anosognosia and those without anosognosia	Migliorelli et al. (1995)
Concurrent validity	104 patients with Alzheimer's disease	Patients with anosognosia had significantly higher scores in all four domains than those who did not have anosognosia	Starkstein et al. (2006)
Neuroimaging	12 patients with Alzheimer's disease with anosognosia and 12 patients with Alzheimer's disease without anosognosia	Patients with anosognosia as measured by the AQ-D had significantly reduced cerebral blood flow in right frontal brain areas.	Starkstein et al. (1995)

Physiologic Variables

The reported lack of consistent findings is not unique to demographic variables. Similar inconsistencies were found in physiologic variables such as EF, New York Heart Association (NYHA) class and blood pressure. The inconsistencies in these studies have been described in Chapter One, and will not be described in detail here. However, it is necessary to describe the methodology and general findings of several studies at this time.

A single group of Italian researchers have published the largest number of studies on the topic of CI in HF. Zuccala and his colleagues in the Gruppo Italiano di Farmacoepidemiologia nell' Anziano continue to produce many articles on this topic. With the exception of the initial study in 1997, all of these studies were performed on patients during their hospitalization, and variables were entered into a database as part of a larger pharmacoepidemiological study. Data was collected by trained individuals at specific time intervals during the hospitalization and continuing through discharge. Data collection took place during predetermined intervals in 1988, 1991, 1993, 1995 and 1997 (Pahor et al., 1996). Various cohorts of participants were subsequently examined in retrospective analyses.

In their first published study, Zuccala et al. (1997) examined 57 patients with HF admitted to the hospital. Cognitive function was assessed with the MMSE. Other data, including the Center for Epidemiological Studies Depression Scale, Katz Activities of Daily Living Scale, physical examination findings, serum laboratory levels and echocardiography findings were collected. Cognitive impairment was found to be present in 53% of the participants. Lower MMSE scores were weakly correlated with lower serum sodium ($r=0.3$, $p=0.02$), increasing age ($r=-.31$, $p=0.02$), higher NYHA class ($r=-.51$, $p=0.001$), and lower left ventricular EF ($r=0.38$, $p=0.007$). When significant variables were entered into an age and gender adjusted regression model, both age and left ventricular EF predicted MMSE scores. Later studies performed by Zuccala and associates have utilized the AMT instead of the MMSE to screen for CI.

In a subsequent publication, Zuccala, Marzetti et al. (2005) examined data of 1,511 participants with HF enrolled into the study in 1993, 1995 and 1997. These participants were screened for CI with the AMT. Demographic data, comorbidity data, medications used, serum chemistry values, and systolic blood pressure were analyzed with logistic regression. The final summary age and gender adjusted model indicated that age, level of education, presence of coronary artery disease, Charlson comorbidity score, systolic blood pressure, anemia, and serum sodium, potassium, glucose, and albumin predicted CI. Some of these findings were contradicted in a smaller study by Riegel et al. (2002). In this study there was no relationship between CI, age, education and systolic blood pressure. The study performed by Riegel will be discussed fully later, but in brief, had a much smaller sample size.

Ejection Fraction

Generally speaking, EF is a commonly studied variable in HF. However, the relationship of EF to CI in subjects with HF is unclear. Many studies have linked decreased EF to CI in HF (Almeida & Tamai, 2001; Sauve and Bennett, 1999), while others have not demonstrated this relationship (Bornstein et al., 1995; Callegari et al., 2002; Sauve & Bennett, 2000; Wolfe et al., 2006). Perhaps differences in the measurement of EF may explain these contradictory findings as, many investigators have questioned the accuracy of EF measurement by echocardiography. Grothues, Smith, Moon, Bellenger, Collins, Klein et al. (2002) studied reproducibility of ejection fraction measurement by echocardiogram and magnetic resonance scanning. Each of sixty

participants had two echocardiograms and two magnetic resonance scans performed and a single investigator analyzed the images. Reproducibility of EF measurements was higher in the magnetic resonance group than in the echocardiogram group. In another study, McGowan and Cleland (2003) performed a meta-analysis of studies comparing accuracy of ejection fraction measurement by echocardiogram to the criterion of radionuclide imaging. Once again, ejection fraction measurement by echocardiography compared poorly to measurements by radionuclide imaging.

New York Heart Association Functional Class

Similar conflicting results were noted when the variable of NYHA class was considered. Many investigators have associated increasing NYHA class with CI (Incalzi, et al., 2003; Trojano et al., 2003), while still others have not made this observation (Callegari et al., 2002; Gorkin et al., 1993; Sauve and Bennett, 2000). When considering the findings of the previous studies, it is important to consider that New York Heart Functional Class designation is highly subjective and depends upon the ability of the person with HF to accurately recall symptoms. Since it has been inferred that individuals with HF may not be able to accurately recognize, evaluate or recall symptoms, the utilization of this variable in studies of HF and cognitive status, while convenient, should be carefully considered.

Effect of Angiotensin Converting Enzyme Inhibitors

In addition to physiologic variables researchers have also investigated the effect of various drugs to treat HF on cognition. In studies of individuals recovering from a

stroke, angiotensin converting enzyme (ACE) inhibitors were found to prevent further cognitive decline (Tzourio et al., 2003). This was also described by Zuccala, Onder et al. (2005), who studied the effect of initiating ACE inhibitors on cognitive function in HF. One thousand, two hundred and twenty hospitalized patients hospitalized were screened for CI with the AMT. Among those participants who were not on ACE inhibitors at admission, AMT scores improved in 30% of those started on ACE inhibitors and only 22% of those who were not ($p=.001$).

In addition to the fact that there is little consistency in reported associations between CI and other variables in HF, there is also concern regarding study design. Published studies thus far have only examined limited subsets of the larger population of HF. For example, the group of authors publishing the largest series of studies utilized hospitalized participants in Italy. These participants were predominantly female and with low educational levels (Zuccala et al., 1997; Zuccala et al., 2003; Zuccala, Marzetti et al., 2005; Zuccala, Onder et al., 2005; Zuccala, Onder, Pedone Carosella et al., 2001; Zuccala, Onder, Pedone, Cocchi et al., 2001). Utilization of these large data sets allow for multiple analysis, and indeed some of the replication in study findings from this group may be due to the fact that specific cohorts of participants were examined for several analysis with significant overlap in study cohorts. Finally, data sets were collected repeatedly and at specific intervals no less than ten years previously. Data collected does not represent a contemporary sample.

It is also worth noting that there is tremendous variability in measurement of cognitive status. Many studies utilized only brief cognitive screening measures that are not sensitive to mild cognitive impairment or do not assess the domains of cognition known to be impaired in HF when measured by comprehensive cognitive batteries. Still other studies do not describe the specific measure. On the other hand, comprehensive batteries used for other studies limit the possibility that specific areas of impairment will be missed, but these batteries are long, impose a significant participant burden and may be affected by subject fatigue.

Outcomes and Behaviors

While most research in this area focused on physiologic variables, a few studies examined the relationship between CI and various outcomes or behaviors. One such study described the relationship between mortality and CI in patients with HF. Zuccala et al. (2003) evaluated 1113 hospitalized patients with HF in Italy. Participants in the sample found to have CI had a higher mortality rate than those without CI. While the results of this study seem compelling, it is important to remember that CI is associated with increased mortality in the general population (Kelman et al., 1994; Stump et al., 2001). Is the increase in mortality seen in the HF group related to the combination of HF and CI or due to the nature of CI in any population?

In another mortality study, Nardi et al. (2007) attempted to determine risk factors for in-hospital mortality among patients with HF. One hundred and forty five patients with HF were enrolled. Cognitive status was assessed with the MMSE, and information

on age, gender, comorbidities, New York Heart Functional Class, ejection fraction, medications used, socioeconomic status, functional status and family support was also collected. Patients who survived their hospital stay were significantly younger, had higher MMSE scores, and had higher Katz index scores. The results of this study support the results of the Zuccala et al. (2003) study, suggesting that CI is a predictor of mortality in this population.

Other studies have focused on the association of CI to disability in patients with HF. Zuccala, Onder, Pedone, Cocchi et al. (2001) evaluated 1,583 hospitalized patients for CI with the AMT. Participants who required assistance with at least one activity of daily living as defined by Katz were considered disabled. Cognitive impairment was noted in 58% of the disabled subjects, but only in 13% of those who were not disabled ($p<.0001$). In logistic regression analysis, CI was associated with an increased odds ratio for disability ($OR=6.49$). One wonders, perhaps, whether this relationship and the relationship between CI and mortality can be explained by another variable, such as age or severity of HF, as opposed to cognitive function alone. In fact, the authors report that in age and gender controlled regression models, age, gender, comorbid conditions, CI, blood pressure and use of ACE inhibitors were significant predictors of disability.

The problem of readmission in those with HF has also been examined. Schwarz and Elman (2003) recruited 156 patient/caregiver dyads to determine the relationship of patient and caregiver characteristics on readmission. The MMSE was used to assess cognitive status. Demographic variables such as age, medications, and socioeconomic

status and predictor variables such as severity of illness, blood pressure, and functional status were entered into a Cox hazard regression model. Cognitive status was not determined to be a significant predictor of readmission. However, it is important to consider that this study involved patient-caregiver dyads. Patients with self-care support may be successful at avoiding readmission regardless of their cognitive status.

Cognitive impairment has also been associated with compliance. Sauve and Bennett (2000) examined memory function and recall in 30 patients with HF. Medication compliance as measured by self-report was compared to deficits in memory and recall. There was no association between medication compliance and CI. However, in those participants with poor medication compliance, half lived alone and most of those had evidence of memory impairment. The authors hypothesized that although medication noncompliance is statistically independent of memory impairment in this sample, the presence of social support may mitigate any true relationship. Surprisingly, literature search of the MEDLINE, CINAHL and PSYCHINFO databases revealed no other published studies on the effect of CI on compliance in HF patients.

To be sure, the relationship between CI and outcome variables such as mortality, disability and readmission takes a particular importance in HF. It might be reasonable to assume that individuals with CI and HF would lack self-care ability and therefore, be more likely to suffer readmission and more likely to be noncompliant with medications. This, at least at first glance, has not been borne out in limited studies. However, in each of the above studies, individuals with HF had caregiver support that may have

ameliorated the effects of CI on self-care behaviors. At the least, studies evaluating the effect of CI on readmission and medication compliance need to be replicated in other groups and with larger samples to determine if any true association exists.

Cardiac Transplant Candidates

Another subset of the HF population that has been widely studied is cardiac transplant candidates. Cardiac transplant candidates represent a convenient group to study. Patients being considered for cardiac transplantation must undergo rigorous testing in the evaluation period, with many centers requiring comprehensive neuropsychological examinations. Additionally, transplant candidates are available for longitudinal follow up and can be utilized for pre- and post-type designs. Putzke et al. (1997) studied 760 transplant candidates with a complex neuropsychological battery. This cognitive battery was lengthy, as it took approximately 150 minutes to complete, and participants performed poorly, with 77% scoring in the impaired range in one test and 35% scoring in the impaired range on five or more tests. Deficiency in a broad range of cognitive domains was noted, including domains of memory, verbal learning, manual speed, mental speed and psychomotor speed. A subsequent case control study (Putzke et al., 2000) revealed that cardiac transplant candidates performed significantly worse than normal controls in several cognitive domains, including psychomotor speed and flexibility, abstract reasoning and problem solving.

Severity of heart failure and its effect on cognitive function was assessed in a study by Petrucci et al. (2006). In this investigation, 252 heart transplant candidates

were grouped by disease severity. The three groups were normal outpatients with HF, patients requiring continuous intravenous inotropes, and finally, those requiring placement of left ventricular assist devices. Cognitive function in the domains of memory, motor speed and mental processing were examined with a range of tests including the Weschler Memory Scale, Trail Making A and B, finger tapping and the Rey Auditory Verbal Learning Test. Statistically significant differences were noted between groups, with evidence of impairment in memory, mental processing and motor speed in the assist device group as compared to normal outpatients. As severity of HF increased, so did the prevalence and depth of CI.

Still other investigators have examined the effect of cardiac transplantation on CI in HF. Schall et al. (1989) examined 20 patients three months after transplant and compared their performance on cognitive tests. The investigators found that there was no difference in cognitive performance after transplant. Alternatively, DeShields et al. (1996) studied 20 patients one year after transplant and found that cognitive domains of memory, attention and orientation were significantly improved compared to prior to transplant. This study supported an earlier study by Bornstein et al. (1995) who compared seven transplanted individuals to four individuals with HF who were not transplanted from an original pool of 62 cardiac transplant candidates. Those individuals who were transplanted experienced improvement in memory, orientation and attention, compared to those who were not transplanted, who experienced no change or decline in cognitive status.

Physiologic markers have been correlated to cognitive performance in this group of patients. Cerebral blood flow studies were performed by Gruhn et al. (2001) in 12 cardiac transplant candidates, 4 cardiac transplant recipients and 12 controls. At baseline, the transplant candidates had lower cerebral blood flow as measured by single photon emission computed tomography as compared to controls ($p < .05$). Cerebral blood flow normalized one month after transplantation in the four participants who were subsequently transplanted. Another group of investigators combined cognitive testing with physiologic studies. Grimm et al. (1996) performed the MMSE and Trail Making A tests with Cognitive P300 evoked potential testing. Cognitive P300 evoked potentials are electrophysiologic measurements of brain responses to specific stimuli (Kuhn, 2003). Fifty five candidates for cardiac transplantation were compared to 55 age and gender matched controls. Twenty-six of the original 55 candidates were later transplanted, and repeat measurement were made. Cognitive P300 peak potentials were abnormal in cardiac transplant candidates compared to controls ($p < .01$), and normalized four months after transplantation. However, these potentials became abnormal again at 12 months, and were similar to values before transplantation. Performance on the Trail Making A test was impaired in transplant candidates compared to controls ($p < .01$), and was not significantly improved after transplant. However, performance on the MMSE improved at four months after transplant ($p < .05$) and remained improved at 12 months. The effect of immunosuppressive drugs in the transplant recipients were implicated in the late deterioration in peak potentials. All things considered, this study represents an important

achievement in this area of study. First of all, this is the only study to combine cognitive testing with some quantification of either cerebral blood flow or cerebral function in a pre/post type design in cardiac transplant recipients. Similarly, a relatively large number of participants were participated in both the pre-transplant and post-transplant phases of testing. However, the unknown effect of immunosuppressive drugs on P300 latencies needs to be determined in order for any specific conclusions can be reached.

Once again, it can be noted that a large number of studies has been performed on a specific subgroup of patients. This repeated use of relatively small subsets of the HF population severely limits the generalizability of study findings to the larger HF population. While transplant candidate represent a convenient group to study, the mere severity of their illness may skew cognitive outcomes. Similarly, the limited number of transplants performed means that only a small segment of the HF population is referred for transplant evaluation. Patients referred for cardiac transplantation typically must meet rigorous financial, social and age related criteria before referral for transplant evaluation is made. Additionally, only a small number of patients are available for post intervention testing, further limiting the generalizability. Finally, little is known about the effect of immunosuppressive medications on cognitive function. Any findings attributed to the status of an individual after transplant must be considered in light of this uncertainty.

Nursing Investigations

Many of the studies performed by nurses in this area have been discussed in previous sections, and will not be included here. Nursing has studied measurement of CI,

readmissions and the effect of specific educational interventions in HF. One of these studies was performed by Riegel et al. (2002). In this study, Riegel evaluated the ability of four cognitive tests to detect CI in HF. Forty-two participants were tested with the Clock Drawing Test, the MMSE, the Boston Diagnostic Aphasia Examination Commands Subtest and the Boston Diagnostic Aphasia Examination Complex Ideational Material Subtest. The test battery used measures general cognitive function, construction abilities, verbal functions and language skills. Thirty-one percent of subjects scored in the impaired range in at least one test, and 28% on more than one test. Cognitive impairment was not correlated with age, education, low blood pressure or serum osmolality. Similarly, there was little agreement between cognitive tests in detecting CI in this group, with the Clock Drawing test detecting impairment in five participants, the Complex Ideational Material subtest in five participants and the MMSE in only one participant. It is important to note here that there is little overlap in terms of cognitive domains assessed by each test. In fact, each test measures different cognitive domains, so it is not surprising that there is no concordance in results on these tests. The lack of a clearly delineated measurement methodology is once again evident in this study.

Schwarz and Elman (2003) studied factors predictive of readmission in patients with HF. In this study, 156 patient-caregiver dyads were examined. Cognitive function of the individual with HF was measured with the MMSE. Of the 128 who completed the study, baseline cognitive function was similar between those readmitted and those not

readmitted. However, those subjects who did not complete the study had poorer cognitive function as measured by the baseline than those who finished.

A similar study was performed by Ekman, Fagererg and Skoog (2001), with a sample of 133 patients (mean age 80.9 years, 67% female gender) admitted to the hospital and randomized to either participate in a nurse managed HF program designed to increase adherence and symptom management strategies, or to standard care by a physician. Cognitive function was measured by the MMSE, and 13.4% of patients were found to be impaired. MMSE scores less than 28 and lower creatinine clearance predicted nonparticipation in the nurse managed program. Traditionally, a MMSE score of less than 24 is considered indicative of CI, so the use of a cut score of 28 is interesting to say the least. Finally, despite the higher threshold, the use of the MMSE alone may underestimate the absolute number of individuals with CI in this study, particularly considering the pattern of deficits noted in heart failure and the age of the participants in this study.

Karlson et al. (2005) studied 208 patients in a project designed to measure the effectiveness of a nurse managed outpatient program for patients with HF. Cognitive function was measured with the MMSE, and the effectiveness of the program was measured with knowledge questionnaires. One hundred three participants were randomized to the intervention group and 105 participants to the control group, who received normal medical care. Of the original 208 participants, 146 completed both the MMSE and the questionnaire at baseline, but only 90 completed the questionnaire six

months later. Twelve percent of participants had MMSE scores less than 24 at baseline. Individuals in the intervention group with CI as evidenced by MMSE score had significantly lower knowledge scores at baseline than those without CI. This difference, however, disappeared after six months in the nurse managed program, suggesting that the knowledge gains in this group were large. The results of this study have important ramifications for nursing, as pointed, tailored educational programs may be developed to assist cognitively impaired individuals perform effective self-management of their HF.

Limitations of Current Research

When evaluating the state of the current science in the area of CI in HF, it is apparent that there is a general lack of consistency among studies. There is no reproducible relationship between CI and physiologic variables such as blood pressure, ejection fraction or New York Heart Functional Class. This lack of consistency extends into cognitive domains, as there is no specific pattern of deficits or even prevalence of CI reported. To be certain, measurement methodology may account for some of this variability, as there is no consistency in cognitive tools used, with the exception of the MMSE. While the MMSE is frequently utilized and is short and well tolerated by patients it has limited ability to detect impairment in memory, executive function and insight and is not sensitive to mild CI. Finally, limited small subsets of the general HF population were used for these studies, limiting their generalizability.

But that being said, is it terribly important to know beyond doubt that an individual with HF and lower ejection fraction is more likely to have CI? Or is it

necessary to know if that individuals with CI likely have lower systolic blood pressure?

Perhaps it is time to focus research efforts in an area likely to prove beneficial to patients.

By understanding the effect CI has on specific outcomes, such as mortality, disability, adherence, readmissions and self-care ability, nursing may improve the quality of life of the millions of people affected with HF.

CHAPTER THREE

METHODS

Introduction and Study Aims

As described previously, the diagnosis of heart failure (HF) brings with it a large burden in terms of self-care practices and knowledge. Self-care is an integral part of the management of HF, and requires that patients are attentive to symptoms, make decisions and evaluate treatment (Riegel, Carlson & Glaser, 2002). Additionally, patients with HF are expected to assimilate a large body of knowledge in order to effectively care for themselves (Adams et al., 2006). Despite the fact that self-care requires intact attention, memory, learning and executive function, persons with HF often have impairment in one or more of these domains of cognition (Bennett & Sauve, 2003). In fact, cognitive impairment has been detected in anywhere from 26% (Zuccala, Onder, Pedone, Cocchi et al., 2001) to 77% (Putzke et al., 1997) of individuals with HF depending on the study reported and the measures used to determine its presence. Although it is widely recognized that CI is a common finding in HF, there have been few studies published to date describing the effect of CI on self-care in HF. That being said, the primary aim of this study is to examine the relationship between cognitive impairment (as manifested by deficits in memory, attention, learning, executive function and anosognosia) in HF and self-care ability. Secondary aims of the proposed study are to examine the relationships between cognitive impairment in HF and hospital admissions and self-care.

Study Design and Rationale

The current study is a correlational design. According to Wood and Brink (1998), correlational study designs are used to assess the relationship between variables not previously described in the literature. Although the proposed relationships are not advanced in the body of knowledge, a conceptual framework supported by the literature can be synthesized to support such relationships. This conceptual framework, as designed by the author, is depicted on page 28. For this study, a body of literature suggests that self-care in HF requires intact attention, memory, decision making, executive function and insight. Another extensive body of knowledge describes deficits in these as well as other domains of cognition in patients with HF. Therefore the study aim, which is to examine the relationship between cognitive impairment (as manifested by deficits in memory, attention, learning, executive function and insight) in HF and self-care ability is well suited to a correlational study design.

Setting

Subjects were recruited for the study from one of two sites; one of the general cardiology clinics at the University of Chicago Medical Center (UCMC), or an outpatient cardiology clinic at one of three Midwest Heart Specialists sites (MHS). The UCMC is a large metropolitan academic medical center with a patient population drawn largely from the immediate geographical area, with a small percentage of patients traveling from more remote areas to receive services there. According to the US Census bureau, the racial composition for ZIP code 60637, which is the ZIP code where UCMC is located, is

13.4% white, 83.2% African American, 0.6% American Indian or Alaskan, 3.5% Asian, 0.1% native Hawaiian and 0.8% some other race. However, the wide geographical distribution of patients at UCMC alters the racial profile slightly.

The Midwest Heart Specialists is a large, suburban multispecialty cardiology group with practice areas dispersed throughout the western suburbs of Chicago. Practice sites included for recruitment included the Naperville, Downers Grove and Winfield sites.

Patients were recruited while attending the outpatient clinic at the UCMC or MHS sites. Initially, any patient meeting inclusion criteria was enrolled, however, after the first 50 participants were enrolled, the inclusion criteria was changed to include participants who had shortness of breath or leg swelling in the previous 90 days of study enrollment. Symptomatic participants are preferred for this study due to scoring issues of the outcome variable, the Self-Care in Heart Failure Index (SCHFI). Self-management scores depend upon symptom recognition and the resultant action on the part of the patient. These actions may include reducing dietary sodium, reducing oral liquids, increasing diuretic dosage or consulting with the healthcare provider. If the participant did not experience either shortness of breath or ankle edema in the previous 90 days, self-management subscale scores cannot be generated, as previously explained. Symptomatic participants were recruited for this study based on the higher likelihood that they would have had symptoms in the last 90 days and to limit the possibility of missing data for this variable. In all, 50 study participants completed the self-management subscale.

All study variables were assessed during a single episode after the recruitment visit, with the exception of admission rates, which were collected 90 days later. Study participants were asked to complete the study visit within 30 days of recruitment either by returning to the outpatient clinic area, or by meeting with the nurse researcher at a mutually agreed upon location, where the cognitive testing took place. Participants were provided with a copy of the SCHFI and the AQ-D to complete and were administered the cognitive tests in their assigned clinic room or other location. The cognitive testing portion of data collection took approximately 40 minutes, and completion of the SCHFI and AQ-D took another ten to fifteen minutes.

Sample

Participants were recruited from patients attending the general cardiology clinics with the diagnosis of HF. There are approximately 1350 unique patients who visit the cardiology clinic each year with the diagnosis of HF at UCMC. The mean age of those seen in the clinic with a diagnosis of HF is 60.1 years, with 52.8% female in gender. The racial composition of those seen with a diagnosis of HF is 55.8% African American, and 28.7% Caucasian (J. Roth, personal communication, March 14, 2011).

A convenience sample of participants were recruited from all eligible patients attending the general cardiology clinic with a diagnosis of HF. In order to protect the privacy of each patient, the nurse researcher recruited patients through the physician and nursing staff directly caring for the potential participant. In order to do this, the nurse researcher attended the outpatient clinics of physicians who agreed to recruitment.

Physicians providing direct care to identified participants contacted the nurse researcher after obtaining assent from the potential participant. Nursing staff also contacted the nurse researcher regarding specific potential participants. The nurse researcher then approached the medical staff caring for the patient to secure patient assent. The nurse researcher subsequently completed a screening form to ascertain that inclusion and exclusion criteria were met. If the patient met eligibility criteria and had no exclusions, the consent process was initiated.

Independent Review

Prior to the initiation of study procedures, approval of the study was obtained from both the Institutional Review Board of the University of Chicago (the study site) and from Loyola University Chicago (the sponsoring institution). Separate review was not required at the MHS site, as MHS employees were not engaged in research, and approval at the primary site (UCMC) was obtained for data collection at that site in the form of protocol amendment. A letter of cooperation is noted in Appendix F.

Inclusion/Exclusion Criteria

In order to be eligible for the study, participants were able to read and understand the English language, have a history of HF for six months or more, and have an ejection fraction of less than or equal to 40%, or moderately reduced left ventricular function, as measured by echocardiography. They must also have had a significant other or caregiver who was able to complete the caregiver portion of the anosognosia tool. After the first 50 participants were recruited, inclusion criteria were changed to recruit only participants

who had symptoms of shortness of breath or leg swelling in the last 90 days. Participants were ineligible to participate if they were over the age of 75, had known cognitive impairment, previously diagnosed dementia, or current substance abuse (drug or alcohol). Specific neurological and psychiatric disorders, such as multiple sclerosis, Parkinson's disease and schizophrenia, were evaluated on a case specific basis.

Measurement

Variables utilized for the proposed study measured the desired variable constructs with acceptable reliability and validity. The Self-Care in Heart Failure Index (SCHFI) was utilized to measure the outcome variable, self-care in HF. As previously described, the SCHFI has acceptable reliability and validity for use in research (Riegel et al., 2004). This index consists of a 15 item self-report questionnaire with three subscales: the self-care maintenance subscale, the self-care management subscale and the self-care self-confidence subscale. Subscale scores are transformed to scale scores of 100, with higher scores indicating better self-care (Riegel et al., 2004). In order to determine if specific cognitive deficits impact these factors, each subscale score was evaluated as separate dependent variables.

A second outcome variable assessed was the number of days hospitalized within 90 days of initial discharge. As previously discussed, it is expected that individuals with HF will participate in self-care activities (Dickson, Riegel & Tkacs, 2007; Riegel & Carlson, 2002). Many authors assert that by properly caring for self, exacerbations of HF and the resultant admissions may be avoided (Carlson et al., 2001). It is hypothesized

that those individuals with low SCHFI scores will be more likely to be admitted than those who have higher SCHFI scores. In addition to a lack of information regarding CI and HF self-care, there is also a lack of empirical data outlining the relationship between self-care and admissions and CI and readmissions among those with HF, therefore this hypothesis is not supported in the literature. A correlational design may help elucidate this relationship.

Independent variables were also measured by instruments designed to measure the construct both accurately and reliably. Cognitive function was measured by the Repeatable Battery of Neuropsychological Status (RBANS), the Controlled Oral Word Association Test (COWAT) and the Anosognosia Questionnaire for Dementia (AQ-D). As previously described, the RBANS is a battery of neurological tests designed originally to detect dementia in the elderly. It consists of twelve subtests and is designed to assess five areas of cognition: immediate memory, visuospatial/constructional, language, attention and delayed memory. Scoring yields a standardized total index score as well as five standardized subscale scores. It took the participants 20-40 minutes to complete the RBANS.

The Anosognosia Questionnaire in Dementia (AQ-D) was used to assess insight. Anosognosia is the inability to recognize one's own impairment, be it physical or psychological (Lezak et al., 2004). It is a lack of insight of one's own disability. The AQ-D is a 30 item questionnaire, on which participants answer questions regarding how frequently they experience specific things. A caregiver is given an alternate form of this

tool, consisting of the same questions. Scoring is based on the disagreement between patient and caregiver responses, the more disagreement, the higher the score. Patients who feel they do not have memory impairment, difficulty understanding what is read in newspaper, or difficulty controlling their bladder, for example, yet their caregivers believe they do, will have poor insight as rated by this questionnaire. In order to measure symptoms specific to HF, two questions were added to this tool. These questions are “How often do you feel short of breath?” and “How often do you have leg swelling?”

Finally, executive function was assessed with the Controlled Oral Word Association (COWAT). The COWAT is a short, easily administered test of verbal fluency, a complex cognitive task that draws upon many cognitive domains, including executive function (Ruff et al, 1997). This test consists of three short (one minute) trials, where the participant is asked to state as many words as possible that begin with a specific letter of the alphabet in one minute. Proper nouns, numbers and variations of the same word (plural forms or those with different endings) are not counted towards the total score. The score is the total number of words stated during the three trials (Lezak et al, 2004).

Cognitive tests were administered by the nurse researcher, who then used published guidelines to score the results. The nurse researcher was trained in administration and scoring of the cognitive tests by an experienced neuropsychologist. Parallel scoring was performed by the nurse researcher and a qualified neuropsychologist or designee until accuracy was demonstrated.

In an effort to control for the effects of social isolation and loneliness on self-care, participants were asked one self-rating question during the study visit. Participants were asked to rate their current level of loneliness on a scale of one to ten, with one being not lonely at all, and ten being the most lonely they could imagine. Participant answers to this question were transcribed by the nurse researcher onto the demographic/screening tool. Values for this question were entered into the multivariate model to assess for the effect of social isolation on self-care.

Power Analysis

In order to ensure that an adequate number of participants would be recruited for the study and to limit the possibility of type 1 and 2 errors, a power analysis assuming an alpha level of 0.05 and beta level of 0.8 was performed. Many different methods for determining sample size for multiple regression have been proposed. One of the more simple methodologies for determining power is described by Nunnally and Bernstein (1994). In order to ensure that beta weights generalize well to other populations, no less than ten participants should be used for each predictor variable or 30 participants for this study. Still others propose utilizing at least ten to twenty participants per variable (StatSoft, Inc, 1984-2003), or 60 participants. An alternative method was proposed by Tabachnick and Fidell in 1996. This method assumes a moderate effect size and involves a simple calculation, $N=50 + 8p$, where N is the number of participants, and p is the number of independent or predictor variables, or $n=74$. Therefore, in order to perform a multiple regression analysis with three independent variables (the RBANS total score,

AQD score and the COWAT total score) against SCHFI subscales and detect a moderate effect size, it was determined that a sample of 70 participants would be required. It was also felt that this sample size would be sufficient for the secondary analysis, since the same number of independent variables would be utilized. Despite the fact that only 50 participants completed the self management subscale, data collection was terminated as interim analysis failed to demonstrate any correlation of self management scores to any cognitive variable.

Procedure

One of the first study procedures involved informed consent. It is important to consider that this study involved recruitment of participants who are vulnerable. In their review article, Sutton, Erlen, Glad and Siminoff (2003) define vulnerable populations as “groups of people who can be harmed, manipulated, coerced or deceived by researchers because of diminished competence, powerlessness or disadvantaged status” (p. 106). Individuals who are considered vulnerable include those that are hospitalized (Alzheimer’s Association, 2004; Jairath, Ulrich & Ley, 2005), those with acute illness (Sutton et al., 2003), those with chronic illness (Alzheimer’s Association, 2004; Sutton et al., 2003) or those with cognitive impairment (Sutton et al., 2003). With this in mind, the consent process for the study was somewhat protracted. First of all, it is important to consider that, although the participants are considered vulnerable by nature of their illness, the cognitive status of the potential participant was not be known at the time of recruitment. It is reasonable to assume, however, based on the prevalence of cognitive

impairment in this population, that a large proportion of potential participants approached for consent would have some degree of cognitive impairment. This placed an obligation on the researcher to make certain that the participant clearly understood the nature of the proposed study, including the consequences of participation or nonparticipation. The potential participant must also demonstrate ability to consider choices and make a choice based on information (Alzheimer's Association, 2004). In order to insure that the participant was making an informed choice, a researcher developed a list of critical points of information relative to the study, including risks, benefits, purpose, time commitment, tools used, compensation (if any), consequences of participation and nonparticipation, and contact information (Jacobson, 2005). An additional point of information unique to the study is the inclusion of an informant. The participant understood that a significant other or caregiver would be asked to complete a questionnaire about the participant. That being said, the nurse researcher for this study explained the key points of the study in clear and easily understood terms and validated the potential participant's understanding of the key points of the study (Steinke, 2004), and only after the researcher was satisfied that the participant fully understood, was consent was obtained. If there was any doubt as to the level of understanding a potential participant may have regarding the proposed study, another person was asked to assess the potential participant's level of understanding and secure a second consent (Jairath, et al., 2005). Potential participants who did not read the consent during their clinic visit, but who were willing to consider

participation, were contacted by telephone using contact information provided by the potential participant. The final approved consent document is located in Appendix G.

Once consent was obtained, participants were given a study number, and all study documents referred to the participant by number only. A table of study numbers and associated participant names was kept in a separate location from other study documents. This list and all study documents, such as consents and test results, were kept in a locked file cabinet in the nurse researcher's locked office. Electronic files such as data files included participant study number only and were kept on a secure laptop computer in the nurse researcher's home. This computer is password protected, and files were also secured with a password. Study files were protected during transport from the study site to the investigator's home office with the use of a Health Insurance Portability and Accountability Act compliant locking bag specifically designed to prevent accidental disclosure of sensitive patient information.

The medical record was reviewed during the clinic visit by the nurse researcher for specific demographic data, such as age, gender, race, level of education, duration of HF diagnosis, New York Heart Association Functional classification and ejection fraction. The Screening/Demographic form, located in Appendix H, was completed during this review, with the exception of the social isolation/loneliness question, which was completed at the outpatient/measurement visit. Participants were questioned directly regarding any items on this form that could not be completed during the chart review. Participants were also asked to identify two or three individuals who would best be able

to complete the caregiver form of the AQ-D. These individuals were contacted by telephone or directly in person during the participant study visit to secure assent.

The nurse researcher then negotiated a suitable time and place with the participant for subsequent cognitive testing. This testing took place either in the Center for Advanced Medicine, Module 5C, the cardiology clinic, the MHS clinic sites or at a mutually agreed upon location within 30 days of the recruitment visit. A multipurpose non-examination room was secured in the area and was used specifically for this purpose. This room was private, removed from the general clinic examination rooms, but yet was located in an area adjacent to the examining physician space. This room is also used for education and interviews by social workers and dieticians in the cardiac and lung transplant programs, but infrequently enough as to support the expected volume and time necessary for this study. Utilization of this room was scheduled through the lead clinic coordinator or her designee. In the event this room was not available, an empty clinic room or other procedure room was used depending on availability. There were no study visits cancelled or postponed due to inability to secure space for the measurement.

Although it was preferred that the participant was accompanied to the measurement visit by the informant/caregiver, it was not necessary. If the informant/caregiver was not able to attend this visit, he or she was contacted by telephone to complete the caregiver portion of the AQ-D after verbal consent was obtained. If the informant/caregiver was present, he or she was asked to complete the informant/caregiver portion of the AQ-D in the clinic waiting area during the time the participant was

undergoing cognitive testing. The participant was escorted to the measurement room and a sign was placed on the door indicating that a study visit is in progress and that the participant should not be disturbed. Participants were asked to complete a medical release form so that medical records from other institutions could be obtained if necessary. The nurse researcher's pager was turned off so as not to be a distracter to the participant.

The order of the cognitive tests performed is subject to debate. Participants with heart failure may be easily prone to the effects of fatigue. Therefore, it was imperative that the measurement visit be as short in duration as possible and that the testing take place in an efficient manner. Although evidence suggests that the order of tests does not affect performance, it is probably beneficial to present the order of tests from the most difficult to the easiest for this population (Lezak et al, 2004). On the other hand, alternating difficult and easier tests may allow for rest in between tests, as well as avoiding participant distress over successive failures (Lezak et al, 2004). Since the RBANS is a cognitive battery that is designed to be administered in a successive fashion, the order of the RBANS as a whole, the AQ-D, the COWAT, the SCHFI and the social isolation/loneliness question must be carefully considered. The social isolation/loneliness question was asked first. Since the RBANS is the most lengthy measure and may be fatiguing to the subject, it was the first cognitive test administered. This was followed by a shorter test, the COWAT. The participants were offered a short break, or even the opportunity to complete the questionnaires during another time and return them in a

postage paid envelope. After a short break, if desired, the participant then completed the SCHFI and the AQ-D. At the conclusion of the study visit, participants were given a gift card to a local bakery shop and a coupon for parking for the duration of the study visit. It took approximately 60 minutes to complete this phase of testing.

In order to determine if CI or self-care ability affects the outcome of admissions to the hospital, admissions were tracked for ninety days after participant study visit. The nurse researcher searched admission records for evidence of readmission of study participants. If a study participant was admitted, the primary reason for admission was evaluated. Any admissions for HF exacerbation were considered an event and subject to analysis. A planned admission for elective surgery or for an unrelated illness would not be subject to analysis. In order to capture those participants who may not be admitted to the center, telephone contact was made with the participant 90 days after the study visit to determine if there had been an admission. In order to determine the nature of the readmission, the admission history and physical and discharge summary were requested from the outside facility. The total number of days hospitalized within 90 days of study visit were considered for analysis. A visit to the emergency department was considered an admission day if intravenous diuretics were given in the emergency room and the patient was released.

Analysis

Data analysis took place using SPSS version 19. Relationships between various cognitive tests and self-care ability were assessed using multiple regression.

Demographic variables of age, gender, race and level of education were utilized to statistically control for differences in cognitive test scores. Group means for demographic as well as dependent and independent variables are displayed in tabular format. Statistical significance was set at $p < 0.05$ and power was set at 0.8 in order to limit the possibility of type 2 error.

In order to determine the exact nature of the relationships between the dependent and independent variables, the statistical analysis consisted of multiple phases. First of all, the unique contribution of each of the cognitive test scores (total RBANS, AQ-D and COWAT) was assessed by univariate regression against the dependent variable, SCHFI scores. By performing this analysis, the unique contributions of the assessed cognitive domains was measured against ability to perform self-care behavior. Secondly, the RBANS subscales measuring attention, memory and learning were assessed similarly, with univariate analysis against the SCHFI scores. The next phase consisted of simultaneously entering all three cognitive test scores (RBANS total score, AQ-D and COWAT) and RBANS subscale scores that were significant predictors in the second phase of analysis into a multivariate model to determine the effect of all variables simultaneously. Finally, the social isolation/loneliness and HF anosognosia scores were entered into the model to examine the effect of each of these variables on HF self-care ability.

Secondary analysis to examine the effect of self-care ability and CI on readmissions were performed in a similar manner, with each independent variable regressed in a univariate model followed by a multivariate technique.

CHAPTER FOUR

RESULTS

Study Aims

As previously stated, the primary aim of this study is to determine the relationship between cognitive function (specifically the effects of memory, learning, attention, insight and executive function) in individuals with HF and self-care ability. Additionally, secondary aims of this study are to determine the relationship between cognitive function and subsequent hospital admission, and self-care ability and subsequent hospital admission.

Analysis

Statistical analysis of the sample characteristics and study variables was performed with the International Business Machines Statistical Package for Social Sciences (IBM SPSS) version 19 ("SPSS for windows, 2010). Demographic characteristics of the participants were analyzed for gender, age, minority race, level of education, and New York Heart Association functional class using frequencies, percentages and measures of central tendency. For categorical variables, frequency distributions were reported. Statistical significance was defined as $p < .05$. Non-parametric comparisons of participant groups were performed with Chi-Square.

Data obtained from the RBANS, SCHFI, AQ-D and COWAT were each analyzed for normal distribution by examining histograms, skewness and kurtosis and

Kolmogorov-Smirnov goodness of fit. The reliability of each study instrument was examined for internal consistency with Cronbach's alpha. Pearson correlation was used to demonstrate relationships between study variables as listed above. Variables demonstrating significant relationships ($p \leq .05$) were entered into a stepwise regression equation to determine if they were predictive of SCHFI self maintenance, self management or self confidence scores (research question one). Additionally, scores on specific cognitive tests were entered into univariate regression to explore the relationship between cognitive domains and self-care ability. Finally, characteristics of participants admitted in the subsequent 90 days versus those who were not admitted were compared with Mann-Whitney U (research question 2).

Sample

Seventy-two participants were recruited from the outpatient clinic area, 59 from Site One and 13 from Site Two, over a 14 month period. Two participants did not return any study instruments, one who could not be contacted, and a second who expired prior to returning any instruments. Both of these participants completed the RBANS and the COWAT, but the results on these measures were excluded from further analysis. Data reported will reflect only the remaining 70 participants. Of the remaining 70 participants, 50 were symptomatic and therefore completed the self-management subscale of the SCHFI, and 20 were not symptomatic, and did not complete this subscale per protocol.

Sample Characteristics

The sample was relatively young (mean age 54.9) and well educated (mean years education 13.9). The distribution of participant age and educational level was negatively skewed and platykurtic. One of the participants in the study completed a doctoral degree and another completed coursework but developed her illness prior to completion of her dissertation study. In order to control for the effects of social isolation and depression, subjects were asked to rate their perceived loneliness on a scale from one to ten, with one being the least lonely and ten being the loneliest. Participants rated their loneliness as low, with a mean loneliness score of 2.8. However, the distribution for loneliness was not a normal distribution, (K-S $Z=.26$, $p<.001$), positively skewed and platykurtic. Loneliness scores were then transformed into Z scores, which were still not representative of a normal distribution. Therefore, loneliness scores were binned into low (participant rating one), medium low (participant rating two), medium high (participant rating three, four, five) and high (participant rating greater than five) loneliness levels. Minority race was also transformed to a dichotomous variable “minority,” with a value of one meaning minority present and zero meaning minority absent.

Sample characteristics for the 70 participants are depicted in Table 11 below.

Table 11. Sample Characteristics

<i>Characteristic</i>		<i>N</i>	<i>Percentage</i>	<i>ADHERE</i>
Site	1	57	81.4%	
	2	13	18.5%	
Gender	Male	38	54.3%	60%
	Female	32	45.7%	40%
Race	Caucasian	30	42.9%	22%
	African American	37	52.9%	
	Hispanic	3	4.3%	

NYHA class	I	21	30%	34%
	II	26	37.1%	
	III	20	28.6%	
	IV	3	4.3%	
	Mean (SD)		Range	ADHERE
Age	54.9 (10.5)		30-75	69.8
Years education	13.9 (2.5)		8-20	
Loneliness raw score	2.8 (2.2)		1-8	
Loneliness (binned)	Low	33	47%	
	Medium low	9	12.9%	
	Medium High	16	22.9%	
	High	12	7.1%	
Medications				
ACE inhibitors			50%	42.5%
Angiotensin receptor blockers			40%	10.9%
Beta blockers			90%	44.2%
Spironolactone			64.3%	11.4%
Digoxin			38.6%	30.4%
Warfarin			37.1%	
Aspirin			50%	
Nitrates			24.3%	
Hydralazine			22.9%	
Potassium			22.9%	
Diuretics			75.7%	65.5%
Loop diuretics			75.7%	
Thiazide diuretics			12.9%	
Inotropes			4.1%	

Participants in the study were prescribed a variety of medications to treat their heart failure, with the majority of patients taking loop diuretics, beta blockers, and aldosterone blockers, and half taking angiotensin converting enzyme inhibitors. A few participants required support with intravenous inotropic medications to maintain adequate cardiac function.

Study participants were placed in NYHA functional class by either their respective cardiologists or a cardiologist member of the research team who was blind to their identity. NYHA classification was based on symptom description by the study participants at the last outpatient visit prior to study enrollment. Forty-seven participants were rated as NYHA class II, indicating that they had symptoms of heart failure with normal activity. A smaller number (20, 28.6%) were described as NYHA class III, having symptoms at less than normal activity, or NYHA class IV (4.3%), having symptoms at rest. Likewise, study participants were advanced in their heart failure, with two participants subsequently requiring ventricular assist device placement, seven on the cardiac transplant list and another eight participants in the evaluation process for cardiac transplantation.

A second site (Site Two) was added to expand recruitment opportunity. Participants from Site One were not significantly different from participants at Site Two in age, years of education, loneliness rating, gender and NYHA class. Participants at Site Two were more likely to be Caucasian than at Site One. For comparison of Site One to Site Two participants, see Table 12 below.

Table 12. Comparison of Site One Participants to Site Two Participants

<i>Characteristic</i>	<i>Site One N=57</i>	<i>Site Two N=13</i>	<i>p</i>
Age	54.43	56.77	.48
Gender	Female=26 Male=31	Female=6 Male=7	.97
Race	Caucasian=18 AA=36 Hispanic=3	Caucasian=12 AA=1 Hispanic=0	<.001
Years education	13.736	14.84	.16

<i>Characteristic</i>	<i>Site 1 N=57</i>	<i>Site 2 N=13</i>	<i>p</i>
NYHA class	Class I=15 Class II=22 Class III=18 Class IV=2	Class I=6 Class II=4 Class III=2 Class IV=1	.40
Loneliness score	3.01	2.00	.08

Descriptive Statistics for Cognitive Variables

Cognitive status of study participants was assessed with the RBANS, the COWAT and the AQ-D. Each tool is described in detail in Chapter 3. A brief overview is provided here.

Repeatable Battery for the Assessment of Neuropsychological Status

The RBANS is a cognitive battery of 12 tests designed as a screening tool for dementia. It was used to assess learning (long term memory index), memory (immediate memory index) and attention (attention index). All study participants completed the RBANS. Raw scores were determined as directed by study manual (Randolph, 1998). Index scores were determined by plotting raw scores for respective tests (list learning and story memory for the immediate memory index, figure copy and line orientation for the visuospatial-constructional index, picture naming and semantic fluency for the language index, digit span and coding for the attention index, and list recall, list recognition, story recall and figure recall for the delayed memory index) on the x and y axis on tables adjusted for participant age. Individual test scores are transformed to scaled index scores during this process, with each subscale as well as total scales scores having a mean of 100 and a standard deviation of 15. Higher scores indicate better cognitive function.

Total RBANS scores range from 40 to 160. Index and total scores of 100 considered normal, and scores less than 70 are considered impaired.

Participants were administered the RBANS by the nurse researcher who was trained in RBANS administration. The nurse researcher also scored the tests as trained by experts in RBANS scoring. Inter-rater reliability between the expert scorer and the nurse researcher was established. Reliability for individual tests was established as $r=.993$, for the indexes as $r=.994$ and agreement for figure copy and figure recall items was 85%. A sample of abnormal tests were reviewed by the expert scorer for accuracy in scoring.

Anosognosia Questionnaire-Dementia

The AQ-D is a 30 item questionnaire designed to assess insight in patients with dementia. It consists of two forms, a patient form and an informant form. The AQ-D score is the difference in scores between caregiver and participant (divergent scores). Of the 70 participants, 63 caregivers completed the parallel version of the AQ-D; five could not be contacted and two declined participation. Accordingly, only 63 AQ-D total scores were obtained, as the total score is determined by subtracting AQ-D participant form scores from AQ-D caregiver scores.

Participants and caregivers who left missing values on the AQ-D were contacted to obtain missing data. After numerous attempts were made to contact participants or caregivers, a total of five questions out of 2100 were left unanswered by participants and 10 out of 1890 were left unanswered by caregivers. Question 22 (How often do you have problems keeping your checkbook, accounts, payments, etc?) was left unanswered by two

participants, and question 17 (How often does the patient have problems controlling his/her sphincters?) and question 26 (How often does the patient have crying episodes?) were left unanswered by two caregivers. All other questions unanswered by either participants or caregivers were only left blank on one occasion. Less than 0.3% of values overall were unanswered. Missing values that could not be completed were calculated by two methods: 1. averaging the completed scores for the unique caregiver or participant and dividing the sum by the number of questions answered (caregiver or participant average), and 2. averaging the scores for all participants or caregivers on that unique question (item mean). In 11 out of 15 cases, unique caregiver or participant averages were within one standard deviation of the item mean for the question. Therefore, participant or caregiver averages were imputed for the missing value.

Caregiver informants were identified by the study participant and were representative of a variety of relationships to the participants. Thirty-five caregivers were spouses, 10 were adult children of the participants, six were significant others, four were friends, three were nieces, three were aunts, one was a granddaughter, and one was a sister.

Controlled Oral Word Association Test

The COWAT is a test of verbal fluency where the examinee is asked to verbalize as many unique words as possible that begin with a specific letter of the alphabet following specific rules. Three different trials are done, and the total score is the number of correct words articulated by the patient in all three trials, adjusted for age, gender and educational level. Higher scores mean better executive function. Scores less than 22 are

considered abnormal. All study participants completed the COWAT, administered by the trained nurse researcher.

Reliability of Cognitive Variables

RBANS index and subscales, COWAT and AQ-D divergent scores were examined for normal distribution as previously described. Internal consistency for each variable was assessed with Cronbach's alpha. Scores for the RBANS subscales and total RBANS were skewed negatively, with the exception of the visuospatial constructional index, which was skewed positively. Likewise, scores for the AQ-D divergent were negatively skewed and platykurtic. Cronbach's alpha for the RBANS total and subscales ranged from .24 for the language index to .79 for the total score. Internal consistency was similar for the AQ-D divergent scores, $\alpha = .84$. For a complete listing statistics relating to distribution and internal consistency of study variables, see Appendix I.

Cognitive Status

Lower scores on the RBANS and subscales as well as the COWAT reflect poorer cognitive status, while higher scores on the AQ-D reflect poorer insight. Scores less than 71 on the RBANS total index or subscales, less than 22 on the COWAT and greater than 32 for AQ-D total were considered below normal and are therefore "impaired" for the purpose of this study. Cognitive status of the participants as defined by study tools is displayed in Table 13.

Table 13. Cognitive Status of Participants

<i>Scale/index</i>	<i>Mean(S.D)</i>	<i>Participant Range</i>	<i>Normal Score</i>	<i>#/% Impaired</i>
RBANS immediate memory (N=70)	87.87 (16.35)	49-120	≥ 70	8/11.4%
RBANS visuo spatial constructional (N=70)	73.74 (13.03)	50-112	≥ 70	31/44.3%
RBANS language (N=70)	92.41 (11.79)	54-114	≥ 70	6/8.6%
RBANS attention (N=70)	90.9 (17.5)	43-135	≥ 70	8/11.4%
RBANS delayed memory (N=70)	87.77 (13.95)	44-110	≥ 70	8/11.4%
RBANS total (N=70)	82.27 (12.79)	51-107	≥ 70	14/20%
COWAT (N=70)	38.7 (10.81)	16-67	≥ 22	2/2.9%
AQ-D participant (N=70)	18.56 (10.26)	2-48		
<i>Scale/index</i>	<i>Mean(S.D)</i>	<i>Participant Range</i>	<i>Normal Score</i>	<i>#/% Impaired</i>
AQ-D caregiver (N=63)	13.78 (9.11)	0-40.34		
AQ-D divergent (dyads)(N=63)	-3.91 (9.26)	-31-14	≤ 32	0/0%

As can be seen from the table above, the cognitive domain most frequently impaired was visuospatial/constructional, followed by immediate memory, attention, delayed memory (as per RBANS scores), language and finally, executive function (as per COWAT). The least often domain affected is insight, (as per AQ-D) with participants typically endorsing more difficulty with day to day activities, than their caregivers endorse of respective participants.

When considering results of all three cognitive tests together, 26 of the 70 (37.1%) participants were impaired in one domain, however, seven were impaired in two domains (10%), four in three domains (5.7%) one in four domains (1.4%) and one in five domains (1.4%). Thirty-one (44.3%) participants demonstrated normal cognitive function across all assessed domains. Overall, participants scored well on the RBANS, with mean scores in the average range for language and attention indexes, low average for immediate memory and delayed memory indexes and total scale, and in the borderline range for visuospatial constructional index. However, a majority (55.7%) of participants were impaired in at least one cognitive domain, with more participants impaired in the visuospatial-constructional domain than any other. Similarly, participants performed well on the COWAT. Of the 70 participants, only two scored in the impaired range on this test of executive function. Finally, none of the 63 participants whose caregivers completed the caregiver form of the AQ-D were found to be impaired in insight.

For descriptive statistics for individual RBANS test scores and AQ-D scores, see . Appendix J and K.

Heart Failure Anosognosia

Participants and their caregivers were asked to rate the frequency of the participant's shortness of breath and leg swelling on a scale similar to the scale for the AQ-D, i.e. never, sometimes, often or always. Participants rated their perceived frequency of symptoms lower than their caregivers, but not statistically lower (paired samples $t=-1.83$, $p=.072$). Similarly, participant scores correlated moderately well to

caregiver scores ($r=.55$, $p<.001$) for both shortness of breath and leg swelling. For descriptive statistics, see Table 14 below.

Table 14. Descriptive Statistics for Heart Failure Anosognosia

<i>Question</i>	<i>N</i>	<i>Mean</i>	<i>SD</i>	<i>Instrument Range</i>	<i>Participant Range</i>
Participant question 1: How often do you have shortness of breath?	69	1.01	.63	0-3	0-3
Participant question 2: How often do you have leg swelling?	69	.83	.82	0-3	0-3
Participant total	69	1.84	1.24	0-6	0-5
Caregiver question 1: How often do you have shortness of breath?	62	1.31	.86	0-3	0-3
Caregiver question 2: How often do you have leg swelling?	63	.87	.77	0-3	0-3
Caregiver total	63	2.19	1.39	0-6	0-6
Divergent question 1: How often do you have shortness of breath?	63	.32	.88	(-)6-6	(-)1-2
Divergent question 2: How often do you have leg swelling?	63	.05	.77	(-)6-6	(-)2-3
Divergent total	62	.37	1.32	(-)6-6	(-)2-5
Divergent scores (binned)		%			
Low	39	63%			
Medium low	11	18%			
Medium high	7	11%			
High	4	6%			

Item analysis of HF anosognosia questions revealed that seven caregivers rated the frequency of shortness of breath at least two categories higher than the participant

(i.e. caregiver designated “often”, participant rated “never”). Alternatively, only one caregiver rated symptoms of leg swelling at least two categories higher than the participant.

Examination of the distribution of the HF anosognosia scores revealed that they were not normally distributed (K-S $Z=1.78$, $p=.004$ for participant, K-S $Z=1.81$, $p=.003$ for caregiver and K-S $Z=1.92$, $p=.001$ for divergent scores). Divergent scores were then transformed into Z scores, which were still not representative of a normal distribution. Similarly, divergent scores were binned into low (divergent score minus two to zero), medium low (divergent score one), medium high (divergent score two) and high (divergent score three to five) values.

Self-care in Heart Failure

Self-care ability in the study sample was assessed with the SCHFI. The SCHFI is a 15 item questionnaire designed to measure three self-care processes: self-care self maintenance, self-care self management and self-care self confidence. Accordingly, there are three subscales, the self-care self maintenance subscale, the self-care self management subscale and the self-care self confidence subscale. All 70 study participants completed the index. However, only symptomatic patients (those who have had symptoms of shortness of breath or leg swelling in the previous 90 days) are able to complete the self-management subscale per protocol. Of the 70 study participants, 50 endorsed symptoms in the previous 90 days and these then completed the self-management subscale.

As with the cognitive variables, SCHFI subscale scores were examined for normal distribution by examining histograms, skewness and kurtosis and Kolmogorov-Smirnov goodness of fit. Internal consistency for each subscale was assessed with Cronbach's alpha and ranged from .48 for the self maintenance subscale to .77 for the self confidence subscale. SCHFI scores were computed as described by Riegel, Lee, Dickson & Carlson (2009). Subscale scores less than 70 are thought to reflect poor self-care ability.

Participant scores on the SCHFI index are summarized below.

Table 15. Self-Care in Heart Failure Index Scores

<i>Subscale</i>	<i>N</i>	<i>Mean (SD)</i>	<i>Range</i>	<i>Cronbach's alpha</i>	<i>% impaired</i>
Self-care self maintenance	70	58.71 (19.52)	20-100	.48	67.1%
Self-care self management	50	61.2 (20.86)	0-100	.63	68%
Self-care self confidence	70	65.67 (20.56)	17-100	.77	62.9%

As shown, participants endorsed poor self-care habits on all three scales. Item analysis revealed lowest mean scores on the questions concerning regular exercise ($X=2.37$, $SD .950$) for the self-maintenance scale, taking an extra water pill for the self-management subscale ($X=2.3$, $SD 1.21$) and confidence that the patient can do something to relieve symptoms for the self-confidence subscale ($X=2.75$, $SD=.891$). Participants were most likely to eat a low salt diet in self-maintenance ($X=3.02$, $SD .816$), reduce the salt in their diet for self-management ($X=3.22$, $SD=1.035$) and generally, most confident that they could recognize changes in their health ($X=3.2$, $SD .714$). For item descriptions, please see Table 16 below.

Table 16. SCHFI Item Descriptive Statistics

<i>Item</i>	<i>N</i>	<i>Mean</i>	<i>SD</i>
How often do you: Weigh yourself daily	70	2.67	1.0
Eat a low salt diet?	70	3.02	.82
Take part in regular physical activity	70	2.37	.95
Keep your weight down?	70	2.68	1.01
Get a flu shot every year?	70	3.01	1.29
How quickly did you recognize it (shortness of breath or leg swelling) as a symptom of heart failure?	50	2.8	1.16
How likely are you to try one of these remedies? Reduce the salt in your diet?	50	3.22	1.04
Reduce your fluid intake?	50	2.94	1.13
Take an extra water pill?	50	2.3	1.21
Call your doctor or nurse for guidelines?	50	2.44	1.18
How sure were you that the remedy helped or not?	50	2.56	1.29
How confident are you that you can evaluate the importance of your symptoms?	70	3.05	.78
Generally, how confident are you that you can recognize changes in your health if they occur?	70	3.2	.71
Generally, how confident are you that you can do something that will relieve your symptoms?	70	2.75	.89
How confident are you that you can evaluate the effectiveness of whatever you do to relieve your symptoms?	70	2.87	.80

Correlations Between Variables

Pearson's correlations were performed between study variables and are displayed in Appendix L.

Cognitive function tests were strongly correlated with each other as well as many demographic variables. Participant age was weakly and negatively correlated with delayed memory index scores ($r = -.32$, $p = .007$) as well as AQ-D participant scores ($r = -.25$, $p = .07$) and caregiver scores ($r = -.37$, $p = .003$). Participants who were older performed better on delayed memory tests than those who were younger. Additionally, participants who were older endorsed less difficulty with activities reported on the AQ-D than those who were younger participants.

Perhaps one of the more consistently related variables to performance on cognitive tests is that of participant education. Years of education is weakly correlated with performance on the list learning ($r = .27$, $p = .029$), story memory ($r = .38$, $p = .001$), picture naming ($r = .31$, $p = .008$), coding ($r = .26$, $p = .028$), list recognition ($r = .29$, $p = .014$), story recall ($r = .40$, $p = .001$), and figure recall ($r = .32$, $p = .007$) and moderately correlated with semantic fluency ($r = .51$, $p < .001$) tests from the RBANS. Accordingly, participant performance on RBANS scales was similarly correlated with education, with years of education correlated with immediate memory ($r = .35$, $p = .003$), language index ($r = .46$, $p < .001$), attention ($r = .32$, $p = .007$) and delayed memory ($r = .45$, $p < .001$) indexes as well as total RBANS ($r = .48$, $p < .001$).

Participant self-reported loneliness correlated weakly with AQ-D-participant scores (participants who were more lonely endorsed more difficulty with activities reported on the AQ-D) ($r = .27$, $p = .023$). Accordingly, participants who reported more loneliness also endorsed lower self confidence on the SCHFI ($r = -.35$, $p = .003$).

While examining the specific correlations on the tests of cognitive function, it is important to consider that the scores on the individual tests are used to formulate scores on the respective scales. For example, scoring on the immediate memory index is based upon scores on the list learning and story memory tests; on the visuospatial/constructional index, the figure copy and line orientation; on the language, semantic fluency and picture naming; for attention, digit span and coding; for delayed memory, list recall, list recognition, story recall and figure recall tests. For a complete listing of correlation between cognitive tests, see Appendix L.

Correlation of Cognitive Variables to Self-Care Variables

Despite the fact that cognitive test scores were correlated with each other, cognitive test scores were not correlated with SCHFI subscale scores. Scores on the SCHFI self-maintenance subscale were weakly correlated with age ($r=.34$, $p=.002$) and scores on the self-management subscale ($r=.43$, $p=.002$). Scores on the self management subscale were weakly correlated with scores on the self-confidence subscale ($r=.35$, $p=.014$), while scores on the self-confidence subscale were weakly correlated with loneliness ($r=-.35$, $p=.003$), list recall ($r=.24$, $p=.047$) and the immediate memory index ($r=.25$, $p=.036$).

Regression of Cognitive Variables Against SCHFI Scales

Hierarchical regression was used to assess the relationship between dependent and independent variables. Controlling variables were entered simultaneously into the regression equation (step one) followed by cognitive variables singly or stepwise (step two), depending on the analysis. Regression was performed as described above with

each SCHFI subscale as the dependent variable against RBANS total score, COWAT and AQ-D divergent scores singly in order to determine the unique contribution of each cognitive variable to SCHFI subscale scores. When controlled for the effect of participant age, gender, minority race and educational level, COWAT scores and AQ-D divergent scores either did not predict a significant amount of variance in the dependent variable or did not significantly add to models predicting SCHFI subscale scores. However, total RBANS scores significantly contributed to the model predicting self confidence scores over the controlling variables (R^2 change .061, $p=.035$), accounting for 15.7% of variance in self confidence scores (ANOVA $p=.048$). Beta weights for variables are listed below.

Table 17. Beta Weights for Total RBANS Against Self Confidence

<i>Model</i>	<i>Standardized Coefficient Beta</i>	<i>p</i>
1 (Constant)		.002
Participant age	.11	.378
Participant gender	-.03	.781
Years education	.01	.936
Minority race	-.26	.046
2 (Constant)		<.001
Participant age	.12	.332
Participant gender	-.04	.756
Years education	.16	.240
Minority race	-.38	.006
RBANS total score	-.32	.035

As noted in model 2, beta weights for minority race and RBANS total score were significant. Note that the relationship is negative, that is higher RBANS scores predict lower self confidence.

In keeping with the proposed analysis, attention was then turned to the individual RBANS subscale scores. None of the RBANS index scores significantly predicted any of the SCHFI subscales when controlled for participant age, gender, years of education or minority race with the exception of immediate memory index scores, which predicted self-care self confidence scores ($R=.215$, $R^2=.154$), accounting for 15.4% of the variance of SCHFI self-confidence scores (ANOVA $F=3.52$, $p=.007$). The correlation between these two variables was indirect, that is, higher immediate memory scores predicted lower self-care self confidence scores. Beta weights for variables are listed below.

Table 18. Beta Weights for Immediate Memory Against Self Confidence Scores

<i>Model</i>	<i>Standardized Coefficient Beta</i>	<i>p</i>
1 (Constant)		.002
Participant age	.11	.378
Participant gender	-.03	.781
Years education	.01	.936
Minority race	-.26	.046
2 (Constant)		<.001
Participant age	.12	.321
Participant gender	-.06	.573
Years education	.14	.249
Minority race	-.32	.009
Immediate memory	-.38	.003

In keeping with the proposed analysis, all three cognitive variables (Total RBANS, COWAT and AQ-D) were entered into a hierarchical regression (step 2, stepwise) with age, gender, years of education and minority race status (step 1, enter) against each SCHFI subscale. In the case of the self maintenance subscale, age, gender, minority race and level of education predicted a significant amount of variance in the self

maintenance scores ($R^2=.215$, ANOVA $F=3.979$, $p=.006$), but none of the cognitive variables entered into the equation. In fact, age alone was a significant predictor of self maintenance scores (standardized coefficient $\beta = .269$, $p=.032$) in this model. In the case of the self management scale, age, gender, minority race and level of education failed to predict a significant amount of variance in the self maintenance scores ($R^2=.131$, ANOVA $F=1.475$, $p=.228$), and none of the cognitive variables entered into the equation. For the self confidence scale, age, gender, minority race and level of education did not alone explain a significant amount of variance in self confidence scores (ANOVA $F=1.631$, $p=.179$), however, stepwise addition of total RBANS scores added significantly to the model ($R^2=.174$, R^2 change $=.073$, $p=.029$). COWAT scores and AQ-D scores did not enter the equation.

The correlation table was then examined for additional variables which significantly correlated to SCHFI subscales. None of the cognitive variables correlated significantly with self-maintenance scores or self management scores. Since neither the self-maintenance scores or the self-management scores were significantly correlated with any cognitive variables, and more importantly, were not predicted in univariate regression by any of the cognitive variables, multivariate regression was not performed with these dependent variables.

Attention was then turned to regression for self confidence scores. Both total RBANS scores and immediate memory index models significantly predicted self confidence when controlled for the effect of age, gender, minority race and educational level with similar R^2 values. However, the R^2 change reached a higher level of

significance for the immediate memory index than for the RBANS total scale and the beta weight for immediate memory was higher than the beta weight for total RBANS in similar analysis (beta weight .38 versus .32). Immediate memory was then chosen for the final model to describe the exact nature of the cognitive impairment contributing to the model.

In keeping with the proposed analysis, loneliness and HF anosognosia were now added to the model as controlling variables. For this purpose, binned loneliness scores were converted to dummy variables and entered in the regression as binary variables with high loneliness and high HF anosognosia as the comparators. Therefore hierarchical regressing entered age, gender, level of education, minority race, low loneliness, low medium loneliness, medium high loneliness, low HF anosognosia, low medium HF anosognosia and medium high HF anosognosia in step 1 and immediate memory index scores in step 2 of the equation.

The initial model (model one corresponding to step one) did not explain a significant amount of variance in self confidence scores (ANOVA $F=1.534$, $p=.155$). However, addition of immediate memory scores still explained a significant amount of variance (ANOVA $F=2.16$, $p=.033$) and contributed a significant amount to the model (R^2 change .092, $p=.013$). Beta weights are depicted below.

Table 19. Beta Weights for Total Model Against Self Confidence Scores

<i>Model</i>	<i>Standardized Coefficient Beta</i>	<i>p</i>
1 (Constant)		.088
Participant age	.09	.516
Participant gender	.06	.660
Years education	.02	.888
Minority race	-.31	.032
Low loneliness	.55	.006
Low medium loneliness	.36	.042
Medium high loneliness	.38	.035
Low HF anosognosia	-.09	.730
Low med HF anosognosia	-.15	.529
Med high HF anosognosia	-.15	.492
2 (Constant)		.008
Participant age	.08	.575
Participant gender	.002	.985
Years education	.13	.324
Minority race	-.37	.010
Low loneliness	.49	.010
Low medium loneliness	.34	.045
Medium high loneliness	.33	.056
Low HF anosognosia	-.04	.878
Low med HF anosognosia	-.10	.643
Med high HF anosognosia	-.11	.596
Immediate memory index	-.34	.013

Because beta weights for age, gender, years of education, HF anosognosia (all variables) and medium high loneliness were not significant, in the interest of parsimony, these variables were removed and the regression repeated. The resultant model also explained a significant amount of variance in self confidence scores, but medium high loneliness no longer contributed to the model and was removed. A third model was run utilizing minority race, low loneliness and immediate memory to self confidence scores.

For the resultant model, a significant amount of variance was explained ($R^2=.223$, ANOVA $F=6.31$, $p=.001$). Beta weights for the variables are listed below.

Table 20. Beta Weights for Model Loneliness, Minority Race, Immediate Memory Against Self confidence

<i>Model</i>	<i>Standardized Coefficient Beta</i>	<i>p</i>
1 (Constant)		<.001
Minority race	-.27	.023
Low loneliness	.20	.083
2 (Constant)		.000
Minority race	-.33	.005
Low loneliness	.21	.059
Immediate memory	-.32	.005

Despite the fact that beta weight for low loneliness indicated it did not contribute significantly to the model, the beta weight approached significance and it was left in the model. Therefore a 22.3% of the variance in self confidence scores was explained by absence of minority race, low loneliness and immediate memory index scores.

Tests of Assumptions of Multivariate Regression Analysis

Histograms and plots were inspected to ensure normal distribution of residuals. Standardized residual against standardized predicted values were randomly scattered around a horizontal line, systematic patterns were not present. Additionally, the histogram of frequency of standardized residual values was normally distributed and only one case (25) was greater than two standard deviations from the mean. According to Stevens (2002), 95% of standardized residuals should lie within two standard deviations from the mean, or no more than three cases. Finally, the normal probability plot demonstrated points close to the diagonal probability line.

The presence of influential cases was evaluated by examining centered leverage values. According to Field (2009), $2(P + 1) / 70$, or 0.114, as recommended by Hoaglin and Welsh was used as a cut point. There were no cases with values greater than .114. Attention was then turned to Cooks distance. Again, according to Field, Cooks distance scores greater than one should be investigated. Examination of the residuals statistics table revealed no cases with Cooks distances greater than one. Finally, there was an acceptable Durbin-Watson statistic (2.173), meaning that regression residuals are not correlated to each other (Field, 2009).

Lastly, to evaluate for multicollinearity in the data, the correlation matrix was examined for evidence of highly correlated variables, and none of the independent variables were significantly correlated to each other. According to Field (2009), variance inflation factor levels greater than ten are problematic. Variance inflation factors for the final model ranged from 1.012 to 1.045. Similarly, tolerance scores were greater than .1 (range .957 to .998). There was no collinearity among the variables.

Earlier, it was demonstrated that increasing age correlated with better scores on the RBANS delayed memory subscale. Additional analysis was performed to determine the exact nature of the relationship between delayed memory and age. Multivariate regression analysis with delayed memory scores as the dependent variable and age, gender, educational level and presence of minority as the predictor variables revealed that, when controlled for the effect of minority, gender and educational level, age did not significantly predict delayed memory scores (standardized coefficient Beta = .201, $p = .065$)

Admission Days: Secondary Aims

Participants were contacted 90 days after study entry to determine if they had a hospital admission since study enrollment. Discharge summaries of the participants who were admitted to the hospital were obtained and examined for cause of admission and hospital course. Admissions were classified as heart failure exacerbation by the attending physician, or if unclear, by the physician member of the research team. Of the 70 participants, 68 were able to be contacted regarding admission. Of those 68, 15 participants were admitted to the hospital during the 90 day follow up period, five for heart failure exacerbation and 10 for another reason. Two participants were admitted for elective left ventricular assist device placement and four for cardiac transplantation therefore follow up ceased with these admissions as heart failure self-care concerns were no longer applicable. Several other patients were admitted for non heart failure related problems, such as intravenous catheter infection, cellulitis, shoulder pain, complications related to gastric banding procedures or chest pain. Participants were followed for a mean of 84.3 days.

Of those admitted for heart failure exacerbations, there were a total of five admission events for a total of 20 days spent in the hospital. Although the initial study design proposed multiple regression to determine if either SCHFI subscales or cognitive function predicted admission, there were too few events to serve as a dependent variable (C. Liao, March 4, 2011). Therefore, although this study was not powered for multiple comparisons, mean differences in cognitive variables and SCHFI subscales were assessed between those admitted and those who were not admitted.

Mann Whitney U tests were used to examine the differences between means of SCHFI subscales and cognitive tests results between groups (those admitted versus those not admitted). Two tailed power was set at .05. There were no significant differences between participants who were admitted to the hospital and those who were not in terms of self-care self maintenance, self-care self management, self care self confidence, immediate memory, visuospatial constructional, attention, language, or delayed memory indexes, total RBANS score or COWAT scores. Anosognosia Questionnaire for Dementia divergent scores differed significantly by group membership (Mdn= 61.5), and AQ-D participant scores (Mdn=66.5) differed significantly by group membership. See Table 21 for comparisons.

Table 21. Comparisons Between Participants Admitted and not Admitted

<i>Variable N</i>	<i>Mann Whitney Test Statistic</i>	<i>Mann Whitney Z score</i>	<i>p</i>
Loneliness (N=68)	131	-.66	.527
Immediate memory(N=68)	129	-.67	.517
Visuospatial/constructional (N=68)	132	-.60	.561
Language (N=68)	119	-.91	.379
Attention (N=68)	142	-.35	.736
Delayed memory (N=68)	121.5	-.85	.412
Total RBANS (N=68)	133	-.58	.579
COWAT (N=68)	111	-1.09	.286
AQ-D participant (N=68)	66.5	-2.14	.030

<i>Variable N</i>	<i>Mann Whitney Test Statistic</i>	<i>Mann Whitney Z score</i>	<i>p</i>
AQ-D caregiver (N=62)	138	-.12	.915
AQ-D divergent (N=62)	61.5	-2.10	.034
SCHFI self maintenance (N=68)	135	-.53	.610
SCHFI self management (N=68)	90.5	-.58	.580
SCHFI self confidence (N=68)	118	-.94	.355
Heart Failure anosognosia (N=60)	75.5	-1.73	.093

Evaluation of the ranks for divergent AQ-D scores and participant AQ-D scores reveals that the rank of those participants admitted was higher for participant scores (rank=52.7 for those admitted versus 33.06 for those not admitted) but lower for divergent scores (rank 15.3 for those admitted versus 132.92 for those not admitted). Despite the fact that the differences were significant, the calculated effect size ($r=Z/\sqrt{N}$) was small for both AQ-D divergent and participant scores. See Table 22 below.

Table 22. Mann Whitney Ranks for AQ-D Divergent and Participant Scores

	<i>Admitted</i>	<i>Not Admitted</i>	<i>Effect Size</i>
AQ-D Divergent	15.3	132.92	.266
AQ-D Participant	52.7	33.06	.259

It is important to remember that AQ-D divergent scores are calculated based on the difference between participant and caregiver scores, positive scores meaning the caregiver endorsed more difficulty than the participant, negative scores meaning the

participant endorse more difficulty. Evaluation of AQ-D divergent scores revealed a negative mean score ($X = -3.91$, S.D. 9.26, range -31-14), meaning as a group, participants endorsed more difficulty than the caregivers. It appears that participants who had higher scores on the AQ-D were more likely to be admitted as well as those whose divergent scores were lower, meaning that they endorse more difficulty on the AQ-D than their caregivers reported for them. However, when Bonferroni's correction for multiple comparisons is considered, this difference is no longer significant ($.05/15 = .003$).

Important Results of this Study

1. A large proportion (52.9%) of participants in this study were African American.
2. The sample was well educated, relatively young and endorsed low levels of loneliness.
3. The sample was well medicated, with 90% on beta blockers and 90% on either angiotensin converting enzyme inhibitors or angiotensin receptor blockers.
4. Most participants were impaired in the visuospatial/constructional domain, followed by immediate memory and attention.
5. Fourteen percent of participants were impaired in global cognitive function. The Anosognosia Questionnaire for Dementia failed to detect lack of insight in the study sample.
6. Most participants were impaired in at least one cognitive domain.
7. The majority of participants reported poor self care practices on one or more of the three SCHFI subscales.
8. Participants were not likely to exercise daily, take an extra water pill if they had symptoms, or feel like they could do something to relieve their symptoms.
9. Participants were most likely to eat a low salt diet, reduce salt in their diet in response to symptoms, and feel like they could recognize changes in their health.
10. Participants who were more educated performed better on immediate memory, attention, language and delayed memory tasks.

11. Participants reporting more loneliness endorsed lower self-confidence scores.
12. Cognitive tests were moderately correlated with each other, but not correlated to SCHFI subscales, with the exception of immediate memory, which was negatively correlated to self confidence scores.
13. Participants rated their heart failure symptoms as occurring less frequently than their care givers reported, but not significantly less.
14. Participants and caregivers disagreed more often on symptoms of shortness of breath compared to leg swelling.
15. Cognitive variables failed to predict SCHFI scales scores in univariate regression with the exception of immediate memory and total RBANS scores which predicted self confidence scores.
16. Low loneliness, absence of minority race, and poorer immediate memory scores predicted better self confidence scores in multivariate regression.
17. A small proportion of participants in this study were admitted for heart failure exacerbation.
18. There was no difference in cognitive function or self care scales between those admitted and those not admitted, with the exception of AQ-D scores, with lower divergent scores and higher participant scores meaning participants were more likely to be admitted.

CHAPTER FIVE

DISCUSSION

The primary purpose of this study was to determine the relationship between cognitive function and self care ability in patients with heart failure. Secondary aims of this study were to determine the relationship between cognitive function and subsequent hospital admission, and between self-care ability and subsequent hospital admission. Discussion of the study will begin with a description of the sample, comparison of study sample and results to other studies, discussion of the limitations of the current study and articulation of the contribution of this study to the science of nursing.

Sample

The study sample was relatively young (mean age 54.9) and well educated (mean years education 13.9). Published studies of CI in HF reported a wide range of mean participant ages, from of 44 (Schall, et al., 1989) to 81 years of age (Ekman, et al., 2001), placing the mean age of participants in this study solidly in the middle of the range. On the other hand, most studies of CI in HF in which educational level was reported involved participants less educated than in this study. Stanek, et al. (2009), however, reported a mean educational level of 14.89 years, Putzke, et al., (2000) reported mean education levels of 13.3 years and Hoth, Poppas, Moser, Paul and Cohen (2008) and Pressler, et al. (2010) reported mean educational levels of 12.9 years.

Generally speaking, younger, more educated patients score better on cognitive tests than older, less well educated patients (Lezak, et al. 2004). These characteristics of the study sample may have contributed to higher observed cognitive test scores.

There was excellent minority representation (African American 52.9%, Hispanic 4.35) in the study sample, as the ratio of minorities in this study compares favorably to a 2009 report by the National Institutes of Health (NIH), where 28.6% (15.8% African American and 4.6% Hispanic) of research subjects in extramural and intramural funded clinical research in 2008 were minorities. Likewise, there is a greater proportion of African Americans in this study than other studies of CI in HF, with the exception of studies primarily aimed at that population (Akamolafe, et al., 2005). There is a large proportion of males in this study, perhaps representative of the disproportionate number of males affected by heart failure (Roger, et al., 2011). However, this study still has a higher proportion of women (45.7%) than most studies of CI in HF.

Participants in this study were prescribed a variety of medications to treat their heart failure in proportions consistent with the ADHERE database (Yancy, Lopatin, Stevenson, DeMarco, & Fonarow, 2006). Unlike the ADHERE database, more participants in this study were receiving spironolactone (64% versus 11.4%) as well as angiotensin receptor blockers (42.5% versus 10.9%). Consistent with the hospitalized nature of participants in this database, 34% had symptoms indicative of NYHA Class IV HF as opposed to 3.4% in this study. Although not many studies have examined the effect of medications on cognitive function in HF, Tzourio, et al. (2003) found that

patients receiving angiotensin converting enzyme inhibitors had a decreased risk of cognitive decline, and Zuccala, et al. (2005) also found that participants started on angiotensin converting enzyme inhibitors had improved cognitive function compared to those not started on this medication. The medical therapy of this sample may have likewise affected cognitive test performance.

Cognitive Measures

Cognitive measures utilized in this study include the RBANS, the COWAT and the AQ-D. Results relative to each of these measures will be individually discussed below.

Repeatable Battery for the Assessment of Neuropsychological Status

The RBANS was used as a measure of global cognitive function and more specifically to assess domains of learning, memory and attention. Mean scores for this battery were mostly in the average range (language or attention) or low average range (immediate memory, delayed memory and total battery), although scores for the visuospatial construction index were in the borderline range. Despite the fact that the RBANS is a relatively short cognitive battery and should be well tolerated by individuals who have limited endurance, it has only been utilized in three other published studies in the HF population. Hoth, et al. (2010) performed cognitive assessment on 27 patients (mean age 68.4 years, level of education 12.2 years) before and after bi-ventricular pacemaker implantation. Baseline scores on the RBANS were slightly better than those obtained in this study, particularly on the visuospatial/constructional index, with mean scores for the immediate memory index of 92.67, delayed memory index of 95.11, language index of

101.19, visuospatial/constructional index of 98.22, attention index of 92 and total battery of 94.22, placing performance across all indexes in the normal range. Similarly, Hoth, et al. (2008) measured cognitive function on 31 participants (mean age 69.1 years, level of education 12.9 years) with the RBANS and found scores to be similar, with immediate memory index mean score of 92.7, delayed memory index of 94.4, visuospatial/constructional index of 96, language index of 100.4, attention index of 90.3 and total scores of 92.7. These findings are particularly compelling, considering that both samples are older and less well educated than the current study sample, favoring lower scores on cognitive testing.

On the other hand, Wolfe, et al (2006) used the RBANS in a study of 38 participants with heart failure and found that mean scores in the language, attention, immediate memory and delayed memory indexes were in the average range, with visuospatial/constructional index and total scale in the low average range. Relatively few other studies have specifically described impairment in the visuospatial/constructional domain as most studies have used simple cognitive tests such as the MMSE to measure global cognitive function. Callegari, et al. (2002) reported that 68% of participants in their study were impaired in visuospatial logical ability. Beer, et al. (2009) used the block design test to compare visuospatial performance of 31 participants with HF to 24 healthy controls and found that participants with HF had significantly lower scores ($t=3.17$, $p=0.002$) than controls. Okonwo, et al (2010) evaluated the performance of 172 older adults with cardiovascular disease on a battery of neuropsychological tests. At baseline, participants with HF had poorer performance on visuospatial skills than other

participants. Similarly, the entire group had the highest decrease in performance during the 36 month study interval in the visuospatial domain. Clearly, investigation of impairment in this domain and its effect on activities of daily living in this population requires further evaluation.

The mean score on the visuospatial/constructional index is lower and the percentage of individuals impaired in this scale is higher than expected by this investigator. The reason for this is unclear. Perhaps the large proportion of females in this study is one explanation, as females tend to perform less well on visuospatial tests than males (Lezak, et al., 2004). Another explanation involves test scoring. One of the tests that comprise the visuospatial/constructional index score is the figure drawing test, which involves subjective assessment of a figure that is copied by the examinee against a set of scoring rules. It is quite possible that another scorer would have scored the tests differently, but this is not likely. On the other hand, co-morbidities (such as diabetes) and impaired visual acuity may have also contributed to this finding. Finally, the proportion of individuals impaired in this domain may be similar to other studies, as proportions impaired are not reported by those investigators.

By far the most frequently described domain impaired in HF is that of memory. Callegari, et al (2002) reported impairment in memory in 73% of participants hospitalized with a HF exacerbation. Putzke, et al. (1997), in a study of 760 cardiac transplant candidates, found participants performed poorly most frequently in domains of verbal learning and memory and tasks of manual speed, psychomotor speed and mental speed. Surprisingly, mean scores for the immediate memory and delayed memory

indexes in the current study were in the low average range, and only 11.4% of participants performed in the impaired range in these domains. One explanation for the relatively low number of participants impaired in this domain is level of education. Of the 70 participants, 63 completed high school and 24 completed a Bachelors degree. In the study by Callegari, 40% of participants had between zero and five years of education, 26.6% between six and eight years of education and 31.3% between nine and thirteen years of education. However, when adjusted for academic achievement, mean scores in both immediate and delayed memory for the group in aggregate were greater than one standard deviation from the RBANS normative group (Randolph, 1998), and still corresponded to the low average range. Yet another plausible explanation is the severity of illness, with most participants being NYHA class I or II, and the fact that this study recruited stable outpatient participants compared to hospitalized patients in the study by Callegari, or transplant candidates in the study by Putzke. Additionally, cognitive testing was performed either in the participant's home, the outpatient clinic area, or in a mutually agreed upon location, compared to the Callegari study, in which participants were administered cognitive testing while hospitalized.

This investigator was not surprised, however in the prevalence of cognitive dysfunction as manifested by total battery scores for the RBANS. Although a relatively high number of participants were impaired in global cognitive function (20%), the study population as a whole scored at the 12th percentile, meaning that 88% of individuals in the normative group as defined by Randolph (1995) scored higher on the total battery than the study group. These findings are particularly compelling when considering the

relatively young and well educated sample in the current study. It is clear that the RBANS was sensitive to cognitive dysfunction in the study group.

The Controlled Oral Word Association Test

The Controlled Oral Word Association Test was used to assess executive function. Of the 70 participants, only two participants (2.9%) scored in the abnormal range for this measure. Measurement of executive function is infrequently reported in HF studies, and when it is assessed, a variety of tools are used. Pressler, et al. (2010) used the Trail Making Part B and COWAT tests to measure executive function on 414 outpatient participants; 249 with HF, 63 healthy volunteers and 102 with other medical illnesses. Participants with HF had significantly poorer performance on the Trail Making B test than those with other medical illnesses, however, scores on the COWAT did not significantly differ between groups. Participants with HF had a mean score of 30 (S.D. 11.9) on the COWAT, with 16% scoring in the impaired range. Wolfe, et al. (2006) used the Wisconsin Card Sorting Test to assess executive function and found that HF participants had higher rates of error across all indexes than age expected norms. Komada, Drews, Sakuraba, Kubo and Heter (2005) used the Trail Making Test and the Wisconsin Card Sorting Test to measure executive function in recipients of heart transplant and compared scores between three groups: those who had not required mechanical support, those who required mechanical support and had thrombus, and those who required mechanical support and did not have thrombus. An additional 11 participants with ongoing mechanical support without transplant were enrolled.

Participants in the mechanical support/thrombus group had significantly poorer scores on both the Wisconsin Card Sort and the Trail Making B test than the other groups.

Dixit, et al. (2010) used the COWAT to measure language performance in 20 outpatient predominantly male participants with HF before and after bi-ventricular pacemaker implantation. Mean score on the COWAT before implant was 47.05. This score is higher than the mean score achieved in this study, and in the normal range of performance. COWAT scores improved after pacemaker implant. Bornstein, et al. (1995) used the COWAT in 62 participants awaiting cardiac transplantation. Bornstein found similar mean scores on this measure (38.3, S.D. 31.2), compared to the current study, but reported a higher proportion of participants impaired (32%). It is important to note that the samples reported in these two studies are quite dissimilar relative to severity of illness.

In addition to the relatively low prevalence of immediate memory and delayed memory impairment, it is also surprising to find a relatively low prevalence of impaired executive function in the study group. While this cannot be easily explained by level of education alone, as raw scores for the COWAT are adjusted for educational achievement, age and gender, it can perhaps be explained by choice of test to measure this domain. Traditionally the COWAT is thought to be a test of verbal fluency (Lezak, et al., 2004), but has gained recognition as a measure of executive function (Bell-McGinty, et al., 2002; Ross, et al., 2007; Ruff, et. al., 1997; Sumerall, et. al., 1997). However, the metacognitive nature of executive function makes it virtually impossible to measure with a single test (Bryan & Luszcz, 2000). Perhaps detection of executive function

impairment in the study group would have improved if the Trail Making Test or the Wisconsin Card Sort Test were used, although prevalence of impairment is not reported in studies using these tools. Additionally, most studies demonstrating higher prevalence of impairment in executive function involved participants who had more severe illness than the study group, such as candidates for cardiac transplantation or those with ventricular assist devices.

Anosognosia Questionnaire-Dementia

Lack of insight or anosognosia of cognitive dysfunction in dementia is frequently studied, however, it has not been frequently studied in other populations. The AQ-D was used in this study in an effort to determine if individuals with HF have anosognosia of their cognitive impairments. Sixty-three of the seventy caregivers completed the parallel form of the tool. As a whole, caregivers rated their respective participant's cognitive difficulties as occurring less frequently than the participant did, that is, participants were aware of their cognitive deficits. While early publications regarding this tool described a cut score of greater than 32 as being indicative of anosognosia, recent publications have suggested scores greater than 14 (Starkstein, Jorge, Mizrahi, Adrian and Robinson, 2007), or scores related to specific factors (Starkstein, et al., 2006). Starkstein et al. (2007) performed a factor analysis of the AQ-D and found that it loaded on four factors: instrumental activities of daily living, behavioral activities of daily living, depression and disinhibition. Criteria for anosognosia for the instrumental activities of daily living would be met if caregivers scored the participant at least two points higher on at least four questions than the participant did (personal communication, Simone Brockman,

2011). None of the participant/caregiver dyads satisfied any of these criteria, that is, there was no anosognosia in the study group.

When considering the reasons behind this finding, one must consider the degree of cognitive impairment present in the study sample. Orfei, et al. (2010) studied anosognosia in 81 participants, 38 with mild Alzheimer's Dementia (AD), 35 with amnesiac mild cognitive impairment and 38 with multiple domain mild cognitive impairment (MCI). Mean AQ-D scores for the amnesiac group and the MCI group were low (-1.40, S.D 9.974 and 0.158, S.D. 11.799), indicating that overall, patients and their caregivers agreed. Similarly, none of the amnesiac patients and only one of the MCI patients met criteria for anosognosia. The findings of this study were supported in a study by Greenop, et al. (2010) in a study of 92 community based participants with cognitive impairment no dementia (CIND) and 91 healthy controls. Mean scores on AQ-D in the CIND group were low ($X=-8.1$, $S.D.=8.1$) and not significantly different than healthy controls, again with most participants describing their cognitive difficulties as more prevalent than their caregivers.

Findings in the current study are similar to the findings described in the previously discussed studies, that is, negative divergent scores. In all of these studies, caregivers endorsed less difficulty with symptoms of cognitive decline than their respective participants, hence the negative divergent scores. There are many reasons that participants and caregivers may disagree on tests such as the AQ-D. One explanation is that caregivers may have a vested interest in portraying their respective patients in a particular way. Additionally, participants may not accurately portray their symptoms to

caregivers. Caregivers may or may not be sufficiently engaged with the day to day activities of the participant such that these symptoms were not likely to be appreciated. Although half of the caregivers in this study were spouses of the respective participants, data was not obtained relative to the amount of time each caregiver spent with the participant in a day. It is quite possible that caregivers were not able to reliably describe symptoms present in their respective participants. Certainly, the utility of measuring congruence between patient and informant questionnaires in this population requires further study.

However, other studies have cast a doubt of suspicion on both self report and informant report in cognitively impaired populations. Vogel, Hasselbalch, Gade, Ziebell and Waldemar (2005) assessed anosognosia in 36 patients with AD and 30 patients with MCI using the Memory Questionnaire. Insight, as assessed by the parallel forms of the Memory Questionnaire, was similar between groups, that is participants with MCI had anosognosia as often as those with AD. Okonkwo, et. al (2009) asked 57 participants with amnesiac MCI and 68 normal controls to perform various activities related to health care and daily living while being observed by study personnel. Participants completed questionnaires relative to these tasks and rated their own perceived ability. Investigators examined the data for agreement between observed performance, self report and informant report. The investigators found that participants with MCI rated their ability on financial abilities higher than actual performance more frequently than the control group. In yet another study, Okonkwo, et. al (2008) compared observed behavior to both self report and informant report in 74 patients with MCI and 73 normal controls. The

investigators found that participants rated their ability significantly higher than observed performance in managing financial activities than did normal controls. Similarly, informants also rated perceived financial ability higher than observed ability in the MCI group compared to controls. The results of these studies indicate that even patients with MCI have some anosognosia of disability. These findings have also been discussed in the HF population. Sloan and Pressler (2009) performed a qualitative study of patients with HF who were found to be cognitively impaired by a comprehensive test battery. Using interpretive phenomenology, the investigators divided the sample into two groups; those recognizing and those not recognizing their deficit at all. Of the 12 participants who were known to be cognitively impaired, four stated that there was no change in their cognitive function.

Heart Failure Specific Anosognosia

If indeed anosognosia for cognitive deficits is not common in this population, is anosognosia for HF symptoms a concern? Quinn, Dunbar and Higgins (2010) attempted to answer this specific question in the HF population. These investigators examined 70 HF participants and their caregivers with the Heart Failure Symptom Survey (HFSS) and the SCHFI. Both participants and caregivers were asked to complete both tools, and scores were analyzed for agreement between pairs. Scores on the SCHFI were not significantly different between dyads, however, scores on the HFSS were different for extremity edema, with participants rating it more severe, $t=0.97$, $p=.01$. Despite the fact that participant rating was significantly higher than caregivers, correlations between caregiver and participant scores were strongest for extremity edema, difficulty

concentrating and dizziness (Spearman $r=.65$, $p=.0001$; $r=.50$, $p=.0001$; and $r=.49$, $p=.0001$ respectively). Poorest correlations were noted on symptoms of bloating and cough. Patient and caregiver scores on the SCHFI did not differ ($t=1.71$, $p=.09$), however, scores on the self-confidence subscale showed a trend towards significance ($t=1.90$, $p=.06$), with caregivers reporting higher scores (better self-confidence) than their respective patients.

Similar findings were reported in this study, with participant and caregiver scores moderately correlated ($r=.554$, $p=.000$), with no significant difference in scores ($t=1.829$, $p=.072$). However, closer examination of individual participant caregiver dyad scores revealed that seven caregivers reported symptoms of shortness of breath occurring more frequently than the participant (divergent scores of two or greater) and one caregiver reporting more leg swelling than the participant. Certainly, further analysis of these findings are necessary, as well as further investigation of anosognosia of HF symptoms in this population.

Self-care in Heart Failure

The SCHFI was used to measure self-care ability in HF and consists of three subscales: self maintenance or those behaviors designed to maintain current level of health; self management, or those behaviors aimed at relieving symptoms that occur; and self confidence. The SCHFI has been modified since its initial release, four questions were added to the self maintenance subscale, one was deleted (keep your weight down), one was added (exercise for 30 minutes) and four were reworded (Version 6). These changes were made to reflect concerns about low reported internal consistency for this

subscale. Two questions were added to the self confidence subscale to reflect self confidence in self maintenance behaviors as well as self management behaviors. Measurement of internal consistency of the revised subscales revealed Cronbach's alpha of .553 for self maintenance, .597 for self management and .827 for self confidence (Riegel, et al. 2009). Version 4 (prior to the above noted changes) was used for this study.

In addition to the above changes, Riegel, et al., (2009) described a revised scoring schema, which was used for this study. With the previous schema, top scores on each subscale were still 100, but lowest possible scores were not 0. The revised formula allowed for a full range of scores from 0-100. Additionally, it was advocated that only individual subscale scores be used, and not total scale scores.

Although relatively low, Cronbach's alpha for SCHFI subscales was comparable to those obtained by Riegel, et al. (2004), as well as other investigators. Dickson, McAuley and Riegel (2008) studied the self-care behaviors of 41 participants relative to employment status. Cronbach's alpha for SCHFI scales in this study were .55 for self maintenance, .65 for self management and .86 for self confidence. Yehle, Sands, Rhynders and Newton (2009) studied the effect of shared advance practice nurse/educational visits versus advanced practice nurse only visits on 52 participants with HF. Participants who participated in shared visits had higher HF knowledge scores than those who did not at the end of the eight week study period, but demonstrated no difference in SCHFI subscale scores. Cronbach's alpha for the SCHFI subscales were slightly higher than this study, with self maintenance alpha=.56, self management

alpha=.70, and self management alpha=.92. Dennison, et al. (2010) evaluated the effect of health literacy on self-care self confidence in patients hospitalized with HF exacerbation. In this study, Cronbach's alpha for the self maintenance subscale was higher (alpha=.72) while self management and self confidence scores were lower (alpha=.56 and .76 respectively) than reported in other studies. Generally speaking, internal consistency of the SCHFI as reported in the current study is similar to that reported in other studies across all subscales, albeit relatively low. Considering the fact that internal consistency was relatively unchanged with later versions of this tool, it is important to continue to refine this measure, and to determine specific groups of patients with HF (perhaps those who are cognitively intact) who may demonstrate improved consistency with this measure.

One of the intriguing findings in the current study is the high prevalence of participant scores falling in the poor range for the three scales. In the current study, 67.1% of participants scores were abnormal for self maintenance, 68% for self management and 62.9% for self confidence. Mean scores for each subscale were also low, with self maintenance 58.7 (SD 19.52), self management 61.2(SD 20.86) and self confidence 65.67(SD 20.56). Yehle, et al (2009) found higher self maintenance scores for both control and intervention group (77.86 and 70.91) but lower scores for the self management and self confidence scales (51.7 and 56.4 for self management; 62.5 and 64.4 for self maintenance) in both groups. However, it is difficult to draw comparisons between these scores and the current study's scores, as although it is not specifically stated, it appears that the scoring schema used was the previously described schema as

total self care scores are reported. A similar pattern of mean scores was described by Cameron, Worrall-Carter, Riegel, Lo and Stewart (2009), where mean scores for self maintenance were 67.8 ± 17.3 , self management 50.04 ± 16.64 and self confidence 62 ± 19.98 . Likewise, Seto, et al. (2011) reported similar mean scores in a large urban multidisciplinary heart failure clinic. Thus it appears that scores for the SCHFI subscales in this study are consistent with other published studies, and that self care practices are universally poor in individuals with HF.

Prevalence of less than adequate scores on SCHFI subscales is also similar to other published studies. Cameron, Worrall-Carter, Page, Riegel, Lo and Stewart (2010) reported that 47% of individuals in their study of CI and self-care had inadequate self maintenance scores, 63% had inadequate self management scores and 56% had inadequate self confidence scores. In an earlier study, Cameron et al. (2009) 48% of participants were inadequate in self maintenance, 88% in self management and 64% in self confidence.

When considering the prevalence of less than adequate self care subscale scores, one must consider the likelihood patients endorse specific behaviors or conditions. Macabasco-O'Connell, Crawford, Stotts, Stewart and Froelicher (2008) investigated self-care practices of indigent patients with participant interview and survey with the SCHFI. Sixty-five participants were recruited from three outpatient clinics and one community hospital. Participants were most likely to take their medicines, talk to their doctors and limit their salt and less likely to weigh themselves daily, exercise and keep an ideal weight. Schnell-Hoehn, Naimark and Tate (2009) discovered similar patterns of self-

maintenance behaviors, with participants most likely to take their medications, talk to their physician and limit the salt in their diet and least likely to weigh daily, exercise and keep an ideal weight. Both of these studies utilized Version 6 of the SCHFI, so again it is difficult to generalize the findings to the current study, but the frequency of reported self care behaviors in these studies is similar to the current study. Perhaps level of cognitive impairment in this study affected the likelihood that participants would intervene on symptoms by taking an extra water pill, but did not affect the likelihood that they would reduce the salt in their diet or call the doctor for guidance. Alternatively, participants in this study felt relatively confident they could evaluate both changes in their health and the importance of their symptoms. This finding is quite interesting, considering the prevalence of CI in the study group as well as the group performance mean on the RBANS. The role of insight may be important here, that is, participants with poor cognitive function may overestimate their cognitive ability or confidence in managing their condition.

Regression of Self-care Variables

This study has failed to demonstrate a relationship between SCHFI subscale scores and cognitive function, with the exception of the effect of immediate memory on self-care self confidence. While the fact that this relationship exists is not itself surprising, the nature of the relationship is surprising, in that decreased immediate memory performance was associated with improved self-care self confidence. The exact reason for this relationship is unclear, but one possible explanation is that patients with better immediate memory appreciate the complexities of managing their disease.

Another possible explanation is that patients with poorer immediate memory have anosognosia of their deficit and are therefore more confident of their self-care decisions. While that may be plausible, it is important to remember that participants in this study did not demonstrate anosognosia as measured by the AQ-D. It is also important to remember that studies of individuals with MCI or CIND failed to demonstrate anosognosia. However, studies by Sloan and Pressler (2009) and Okonkwo, et. al (2008) imply that neither self report or informant report can be relied upon in this population. That being said, the exact nature of this relationship can not be determined with this study, as there was no direct or indirect assessment of the accuracy of the dependent variable, SCHFI scores. To be sure, this area requires further study.

Several investigators have attempted to link self care ability to either health literacy or cognitive function. Yehle, Hess, Plake, Murawski and Mason (2010) found that individuals with higher health literacy were more likely to have better self management and self confidence scores than those who had lower health literacy scores. Similarly, Dennison, et al., (2010) also found that individuals with higher health literacy had improved self confidence scores, but self maintenance, self management and 30 day readmission rates did not differ by health literacy level. To be sure, health literacy does not equate with cognitive function, but perhaps cognitive function mediates health literacy. Further study is required to delineate the relationship between these two constructs.

Cameron, et al., (2010) attempted to relate cognitive function to self care ability. The investigators used the MMSE and the Montreal Cognitive Assessment tool to

measure cognitive function and the SCHFI to measure self-care. Individuals with poorer cognitive function had poorer self management and self confidence scores. Twenty percent of variance in self management scores was predicted by the presence of mild cognitive impairment, NYHA functional class and comorbidity index in multivariate regression. Presence of MCI was the strongest predictor. However, presence of mild cognitive impairment did not predict self confidence scores in multivariate regression.

In another study Cameron, et al. (2009) tested a model of self-care in individuals with HF. Depressive symptoms as measured by the Cardiac Depression Scale, cognitive function as measured by the MMSE, age, gender, social isolation, self-care self confidence and comorbid illness were used to predict self maintenance and self management scores. Cognitive function did not prove to be a significant predictor of either self maintenance or self management, but including cognitive function in the models enabled the models to predict 4% more of the variance in respective scores. Gender, moderate to severe comorbidity, depression and self confidence were significant predictors of self management and age and moderate to severe comorbidity contributed significantly to the self maintenance scores. While the results of these studies do not support the findings of this study relative to self confidence, the results do support the lack of significant findings for the self maintenance and self management subscales.

How then, does one explain the lack of significant findings? Or more importantly, the inverse relationship found in this study? One must remember that the SCHFI is a self reported tool. Neither the two previously reported studies nor the current study included a detailed caregiver report of actual performance relative to the SCHFI.

Considering the high prevalence of CI in the study group, one must allow the possibility that the SCHFI may inaccurately reflect true self care practice. Despite the fact that the study by Quinn, et al. (2010) failed to demonstrate a significant difference in SCHFI scores between patients and caregivers, one must remember that there was no measure of cognitive function in this study.

The Effect of Minority

Important findings in this study center around the influence of minority status on both cognitive test scores and self confidence scores. To be sure, the effect of minority on both of these constructs is difficult to determine. Patton, et al. (2003) administered the RBANS to 50 African American and 50 Caucasian participants who were not cognitively impaired and were matched with respect to age, gender and educational level. African Americans scored significantly lower than the Caucasians on 10 of the 12 subtests and three of the five subscales, as well as the total scale. Many reasons have been proposed for this effect, including quality of education (Randolph, personal communication, March 30, 2011), socioeconomic status, cultural sensitivity of the tool, and attitude of the examinee (Patton, et al., 2003). To be sure, this area requires further study.

Still another area of concern is the issue of minority status and self confidence. Although the relationship between race and performance on the SCHFI has not been described, many studies have addressed the issue of self-efficacy and race. Thomas, et al. (2010) evaluated data on 1199 participants in the Bypass, Angioplasty, Revascularization 2 Diabetes trial. A total of 866 Caucasians and 222 African Americans were studied. In this study, African Americans endorsed lower self-efficacy than Caucasians on self

report. James, Smith and Brice (2010) evaluated self reported adherence to discharge instructions after an emergency room visit. Of the 251 participants, 133 were Caucasian, 69 were African American and 49 were Hispanic. There was no difference in adherence to follow up between ethnic groups, however, African Americans and Hispanics reported difficulty in obtaining follow up appointments as the primary reason for lack of follow up as opposed to the Caucasians, who reported they felt better.

Finally, Bluestein, Valentine, Mead and Regenstein (2008), in a study of 2941 patients discharged from one of ten hospitals, found that minority race/ethnicity was related to decreased self confidence to manage cardiovascular disease. However, when entered into a regression model with socioeconomic status and severity of illness, minority status was no longer a significant predictor. Similarly, Wu, et al. (2010) studied the effect of ethnicity on event free survival in 135 patients with HF, 14 African Americans and 121 Caucasians. Adherence to medication was measured with the Medication Event Monitoring System. African Americans were less likely than Caucasians to be adherent to medical therapy and more likely to be admitted during the three year follow up interval. In Cox survival analysis and multiple regression analysis, the investigators found that medication adherence mediated the effect of minority status on event free survival, that is, event free survival was related to medication adherence and not minority status alone.

So what, then, accounts for the disparity in self-efficacy? Is it a question of access to care, mistrust of health professionals, severity of illness, lack of response to medical therapy, attitudes and beliefs regarding taking medications or health literacy?

Regardless of the cause or causes of this phenomenon, further studies are necessary to delineate this complicated issue.

Admission Days: Secondary Aims

Planned analysis of this research question involved regression, however, due to the low number of admission events, this was not possible. Resultant comparisons of study variables revealed no statistically significant differences in cognitive or self care variables between those participants admitted and those who were not, with the exception of AQ-D divergent scores and AQ-D participant scores. Mann Whitney U comparisons revealed that those admitted had lower AQ-D divergent scores and higher AQ-D participant scores than those not admitted, but the effect size was small. Because this study was not powered for multiple comparisons, the frequency of admission was low (five participants admitted) and the effect size was low, few assumptions can be made from this data. However, one must ponder the relatively low number of hospital admissions in the study group relative to the high prevalence of inadequate self maintenance, self management and self confidence scores. Perhaps advances in medical therapy and the relatively high frequencies of participants on beta blockers and either angiotensin converting enzyme inhibitors or angiotensin receptor blockers contribute to this outcome. Similarly, participants in this study were managed in a multidisciplinary specialty clinic with access to highly educated nursing staff, advanced practice nurses and a social worker in addition to standard medical care. If a patient is adequately supported by such a network of experts, does the burden of self-care weigh as heavily? Finally, study inclusion criteria required that participants have a caregiver who was able to

complete study questionnaires. Perhaps any effect of inadequate self care or cognitive function on the admission outcome was ameliorated by the presence of a caregiver.

Study Limitations

One of the major limitations of this study is sample size. Difficulty with non-normally distributed variables and resultant dummy variables lead to a large number of variables in initial regression equations. This was not considered during original power analysis. Although the study sample was largely minority, the high educational level and young age of the sample makes it difficult to generalize the results of this study to the heart failure population at large. Similarly, this study did not involve participants with heart failure and preserved ejection fraction and cannot be generalized to patients with this condition. Additionally, outcomes in patients who are not managed in similar multidisciplinary HF management programs may not be congruent. Despite the fact that SCHFI scores are low, all participants had caregivers who were interested and involved in their care. This may also contribute to the relative lack of findings relative to self care and admission. Although there was excellent caregiver participation, (63/70), seven caregivers declined to participate, and several participants refused to participate based on the lack of a caregiver. Perhaps the study sample may represent a self-selected group, that is, only those participants who were relatively sure that their caregiver answers would compare favorably with their answers participated. Still another limitation, and a very important one, is the lack of an informant based caregiver report on actual self care practices, or perhaps more importantly, an objective assessment of actual self-care

practices. Finally, although a 90 day follow up period is longer than most studies, longer duration of follow up may provide richer data relating to outcomes.

Important Findings

There are several important findings relative to this research. First of all, patients with HF uniformly perform self-care behaviors poorly, and lack self confidence in their ability to care for themselves. Secondly, there is a high prevalence of cognitive dysfunction in the study group. Thirdly, data from the current study does not support a relationship between cognitive function and self-care. Finally, data from the current study does not support a relationship between either cognitive function or self care and subsequent hospital admission.

Implications for Providers

The findings from this study have led to some important implications for healthcare providers caring for individuals with HF. First of all, healthcare providers caring for individuals with HF rely heavily on self-report of symptoms, medication adherence and response to symptoms. Given the large proportion of study participants impaired in cognitive function and the studies that cast doubt on those individuals' ability to self report symptoms of cognitive dysfunction, can healthcare providers trust these patients to accurately communicate with the healthcare team? When caring for individuals with HF, healthcare providers must be vigilant to signs of cognitive dysfunction and treat with caution any information gleaned from individuals suspected of having cognitive decline. Signs of cognitive dysfunction include inconsistencies in self-report, self reported dysfunction, or spousal or other caregiver endorsed dysfunction. If

present, healthcare providers should seek external validation of self reported information from spouses or other care providers knowledgeable of the patient's current health status and health care behaviors.

That being said, healthcare providers must consider methods to take this further, that is, to independently observe self care behaviors in this population. Perhaps case studies, computer based scenarios or heart failure self-care dilemmas could be utilized to ask patients to draw upon past experiences as described by the naturalistic decision making process advocated by Riegel, and determine hypothetical responses to proposed difficulties. These scenarios, if well designed, would provide an excellent opportunity for healthcare providers to observe, with relative certainty, decision making and self care behaviors in this group of patients.

Additionally, healthcare providers should consider developing protocols for routine screening for cognitive decline in patients with HF. Although it may not be practical to perform routine screening on all patients with HF, as the body of literature in this area expands, healthcare providers may be able develop evidence based screening guidelines for patients at risk for cognitive decline. Based on the current literature, for example, older, female patients, those with advanced heart failure, or those with higher NYHA class, might be candidates for routine screening.

More participants in this study scored in the abnormal range for the visuospatial/construction domain than any other domain. Healthcare providers must be alert for any potential difficulty that patients impaired in this domain face when performing health care related activities of daily living. Patients with impairment in this

domain will have difficulty understanding their place in space, perceiving depth or constructing a whole from smaller parts. More simply put, individuals with visuospatial/constructional impairment may have difficulty driving to their healthcare provider appointments, filling insulin syringes, replicating filled pill boxes, or constructing healthcare items such as blood pressure cuffs, automated scales or even left ventricular assist device equipment.

Still another area of concern for healthcare providers caring for this population revolves around the issue of self-care behaviors and self-confidence. Participants in this study performed poorly across all SCHFI subscales. Therefore healthcare providers are challenged to find opportunities to favorably impact self-care through creative and evidence based interventions. How this can be done remains a question. According to Riegel, self confidence is an important determinant of self-care that positively impacts self maintenance and self management activities. Perhaps by improving self confidence, then self maintenance or self management behaviors may be also be improved.

Many studies have demonstrated that increased self-efficacy is associated with improved self-care behaviors. Schweitzer, et al. (2007) measured self-efficacy with a composite score derived from the self confidence subscale of the SCHFI and an investigator developed tool. Self efficacy predicted adherence to weighing daily, following a fluid restriction, exercising regularly, nonsmoking behavior and alcohol abstinence. Similarly, Cameron, et al. (2009) found that improved self confidence as measured with the SCHFI predicted improved self management scores.

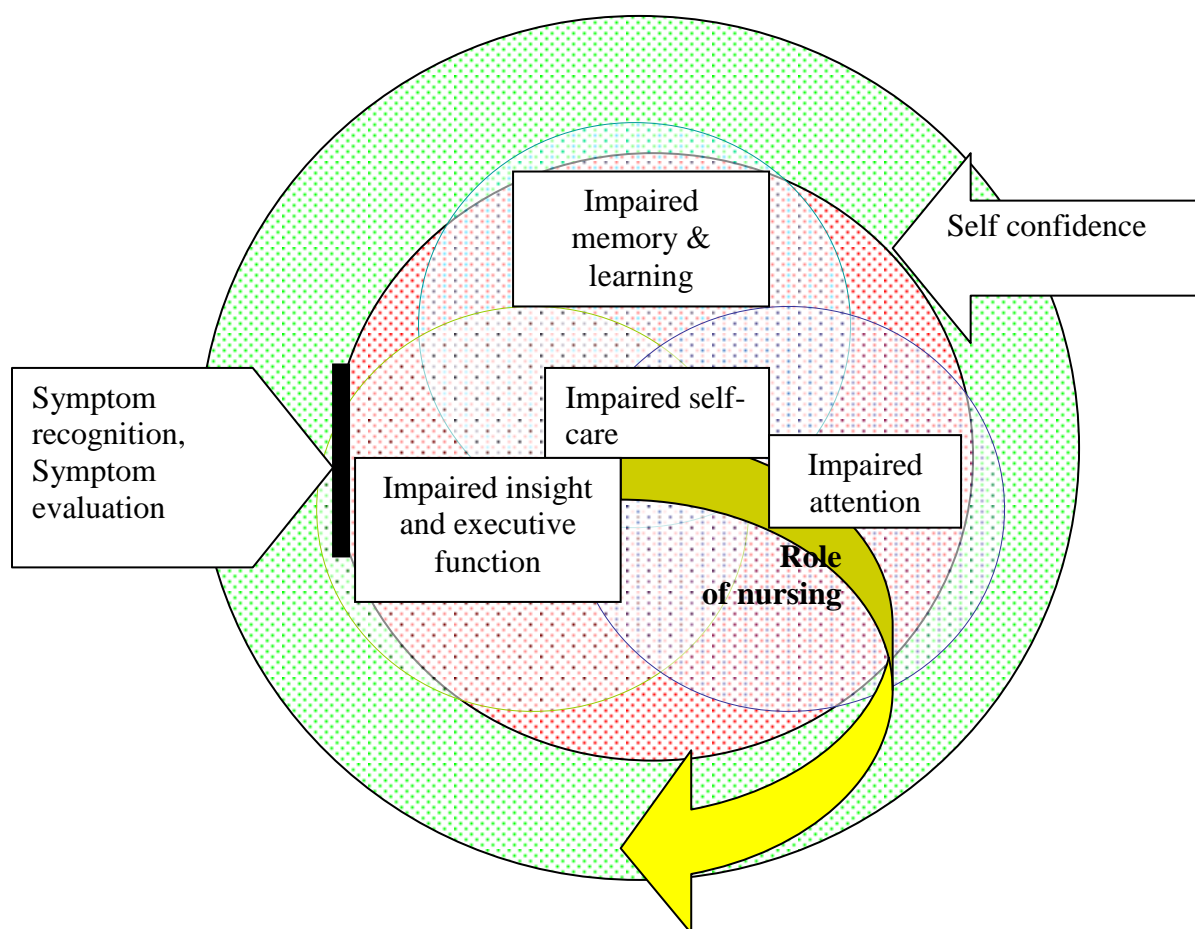
While it appears that improved self confidence or self efficacy improves self care behaviors, methods to improve either self confidence or self efficacy are not as clear. Powell, et al. (2010) attempted to improve self care behaviors in 902 participants hospitalized with HF. Participants were randomized to receive the self management program which included 18 two hour group meetings over a one year interval, along with education fact sheets, or to the education only group which received 18 educational fax sheets by mail followed by a telephone call from the study staff to ascertain understanding from the study staff. There was no difference between groups in mortality, rehospitalization for heart failure, hospitalization for any reason or quality of life. Yehle, et. al. (2009) determined that educational and support visits coupled with regular medical visits did not change SCHFI scores. On the other hand, Seto, et al. (2011) determined during face to face interview, that lack of education about self-care, financial difficulties and patients' attitude about self monitoring were attributed to poorer self-care practices by patients. While education may hold some benefit in improving self confidence, it may not be the answer for all individuals, particularly those with some level of cognitive dysfunction.

Other methods to improve self efficacy have been discussed in the literature, including motivational counseling and peer support. Several studies have evaluated the effectiveness of motivational counseling or interviewing (Paradis, Cossette, Frasure-Smith, Heppell & Guertin, 2010; Riegel, et al, 2006), and have demonstrated improvement in self care behaviors. Similarly, Riegel and Carlson (2004) found that HF

patients participating in a peer support program demonstrated greater improvement in SCHFI scores compared to those not in this program.

Although the results of this study do not support the proposed model, it is this investigators' belief that cognitive function does impact self care. However, perhaps nurses would make the best contribution towards improving self care in this group not by performing more education, but also by investigating ways to improve self confidence, ultimately leading to improved self care. Therefore, the following model is proposed:

Figure 3. Revised Murks' Model of Self Management in Heart Failure



In this model, the inner circle now represents impaired self care. By improving self confidence, through whatever mechanism, the inner impaired self care circle is contracted, minimizing the effect of cognitive impairment in this group.

Implications for Further Research

Further research in this area is necessary. While the results of this study support the relatively high prevalence of CI in the study group, the impact of CI on observed health related activities of daily living remains to be determined. Clinicians rely heavily on patient self report to accurately relay their symptoms, the response to interventions and level of adherence to medical therapy in order to treat the heart failure syndrome. Can clinicians rely on patients? Is there a role for either routine cognitive screening or informant report in this population? Secondly, the role of impairment in visuospatial/constructional domains in this group needs to be addressed, as well as its potential effect on self-care and activity of daily living behaviors. Certainly, more studies are needed to determine the relationship between impairment in this domain and the HF syndrome as well as its effect on health care activities of daily living. Thirdly, reliable and valid tools to assess executive function and anosognosia in this population need to be developed. As alluded to above, the role of informant questionnaires or parallel tools is an important area of research, as the current study suggests that patients rate their symptoms as more severe than caregivers. Research aimed at addressing why this occurs is important in teasing out variability in self care behaviors. Similarly attention needs to be directed at the development of tools to assess either informant reported or observer based health care related activities of daily living. Finally, the

relationship between self-care and cognitive function requires more study. As yet, there are no consistent results describing the relationship between these concepts.

APPENDIX A

STUDIES OF COGNITIVE IMPAIRMENT IN HEART FAILURE

Prevalence

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Akomolafe, Quarshie, Jackson, Thomas, Deffer, Oduwole, . . . Mayberry (2005)	100 African American patients with heart failure	Mini Mental Status Examination, Geriatric Depression Scale	Age, gender, educational level, NYHA class, ejection fraction	Cognitive impairment as determined by MMSE scores less than 24 was present in 10% of study sample	No relationship of cognitive status to age, gender, educational level, ejection fraction or scores on Geriatric Depression Scale	MMSE as cognitive variable.

Prevalence

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Putzke, Williams, Millsaps, Azrin, LaMarche, Bourge, Kirklin, McGiffin & Boll (1997)	760 candidates for cardiac transplantation who underwent extensive neuropsychological testing	Shipley Institute of Living Scale, Weschler Adult Intelligence Scale, Boston Naming Test, COWAT, Grooved Peg Board Test, Trail Making A and B, Symbol Digit Modalities Test, Stroop Neuropsychological Screening Test, Weschler's Memory Scale-Russell's revision, Visual Reproduction Test, Selective Reminding Test, Paired Associate Subtest of Weschler Memory Scale	Age, gender, race, education, marital status, cardiac diagnosis	77% of subjects had one or more test in the impaired range.	As reported in results	Limited to cardiac transplant candidates, not representative sample. Extensive testing, not practical for widespread use.

Prevalence

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Zuccala, Onder, Pedone, Carosella, Pahor, Bernabei & Cocchi (2001)	1,583 subjects with heart failure enrolled in pharmacoepidemiologic study, 12,052 subjects without heart failure in same larger study	Hodkinson Abbreviated Mental Test (AMT)	Demographic and physiologic variables, blood pressure	Cognitive impairment present in 26% of subjects with heart failure at discharge, 19% of controls.	Presence of diabetes, renal disease, chronic pulmonary disease, atrial fibrillation, digitalis or diuretic use, serum sodium, potassium and creatinine.	Retrospective analysis of large database of hospitalized patients, not representative.

Patterns of Impairment

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Almeida & Tamai (2001)	50 consecutive patients admitted to emergency room with heart failure and 30 elderly controls without heart failure	Cambridge Examination for Mental Disorders, MMSE, Trail A & B, Digit Span, Digit Symbol, Letter Cancellation Test	EF, education, history of MI, hypertension, CVA, brain injury, epilepsy, > 20 cigarettes daily, regular alcohol consumption	Deficits noted in memory and attention,	None reported	Recruitment of participants from the emergency room limits generalizability

Patterns of Impairment

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Bornstein, Starling, Myerowitz & Haas (1995)	62 subjects with end stage congestive heart failure undergoing cardiac transplant evaluation. Of these 62, seven transplanted and four non transplanted subjects were retested	Neuropsychological battery consisting of Weschler Adult Intelligence Scale-Revised, Logical Memory and Visual Reproduction tests, Verbal Concept Attainment Test, Wisconsin Card Sort, Trail Making A and B, COWA, Grooved Pegboard Test, Finger Tapping Test, Seashore Rhythm Test, Speed Perception Test, Digit Span and Knox Cube Tests.	Right atrial pressure, left ventricular ejection fraction, pulmonary artery wedge pressure, Cardiac Index, Stroke/volume Index	Subjects overall scores were in the impaired range in over 50% of measures. Sum scores indicate that 58% of subjects scored in the impaired range on 45% or more of the tests. Most impairment was seen in reasoning and concept formation, attention and psychomotor skills.	Impairment Index with pulmonary artery pressure, cardiac index, stroke volume/stroke volume index and ejection fraction	Sample of cardiac transplant candidates not representative of heart failure population, limited number that were transplanted further limits ability to make conclusions.

Patterns of Impairment

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Callegari, Majani, Giardini, Pierobon, Opasich, Cobelli & Tavazzi (2002)	64 patients admitted to the hospital with heart failure exacerbation	Weschler Adult Intelligence Scale, Spinnler and Tognoni Battery	Cardiopulmonary artery exercise testing, right heart catheterization values, ejection fraction as measured by echocardiogram	One in five HF patients had impairment in at least one of five cognitive functions, most in memory, (73%), short term memory (73%), verbal memory and learning (55%), visual spatial logical ability (68%). Only 9% of HF patients did not have impairment in any domain. 30% had more than 4 cognitive functions impaired.		Hospitalized subjects may limit generalizability & overestimate prevalence.

Patterns of Impairment

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Deshields, McDonough, Mannen & Miller (1996)	191 patients referred for cardiac transplantation evaluation. Of this group of 191 patients, 21 were later transplanted and retested one year later.	MMSE, Trail Making A and B, Weschler Memory Scale-Revised, Visual Reproduction and Logical Memory Subtests, the Weschler Vocabulary Subtest and the Blocks Subtest		Scores on Weschler Memory Scale, Verbal subtests were impaired compared to population norms, no other differences noted in mean scores.	Scores on MMSE, Weschler Visual Reproduction test and Weschler Vocabulary tests did not change after transplant.	Sample of cardiac transplant candidates not representative of heart failure population.

Patterns of Impairment

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Grubb, Simpson & Fox (2000)	20 subjects with history of myocardial infarction without congestive heart failure and 20 subjects with history of myocardial infarction and congestive heart failure.	Rivermead Behavioral Memory Test, Digit Span, National Adult Reading Test, Hospital Anxiety and Depression Questionnaire,	New York Heart Functional Class, left ventricular ejection fraction,	Anxiety and depression scores higher in heart failure group. NART scores higher in heart failure group. No difference between groups in memory function or digit span, or Rivermead scores. No difference in frequency of moderate or severe memory impairment between groups.	As reported in results	Etiology of heart failure may confound results.

Patterns of Impairment

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Hoth, Poppas, Moser, Paul & Cohen (2008)	31 participants with heart failure and 31 participants with cardiac disease other than heart failure	Repeatable Battery for the Assessment of Neuropsychological Status, Trail Making A and B, Controlled Oral Word Association, Weschler Adult Intelligence Scale Letter Number Sequencing, Stroop Color Word Test	Ejection fraction as measured by echocardiogram, cardiac index as measured by echocardiogram	Participants with heart failure had worse performance on Trail Making Tests, and the Stroop Interference. Poorer EF correlated with poorer global cognition and executive function. Cardiac index was correlated with immediate memory.	No difference in scores for the Repeatable Battery for the Assessment of Neuropsychological Status, Controlled Oral Word Association, Letter Number Sequencing.	Relatively small sample,

Patterns of Impairment

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Incalzi, Trojano, Acanfora, Crisci, Tarantino, Abete & Rengo (2003)	369 subjects with stable heart failure already enrolled in CHF Italian Study	MMSE, Attentional Matrices, Raven's Coloured Matrices, Categorical Verbal Fluency, Corsi Block Tapping, Rey's Immediate and Delayed Recall	BADL's, IADL's, GDS, NYHA class	Recency, immediate recall, delayed recall and learning were affected. There was only a trend in MMSE scores. MMSE cut point of <24 identified as best, but sensitivity of 54.2% and specificity of 68.8% vs immediate recall and 51.5% and 65.9% vs delayed recall suboptimal.	No etiology	Secondary study, Italian sample limits generalizability

Patterns of Impairment

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Komoda, Thorsten, Sakuraba, Kubo & Hetzer (2005)	19 participants requiring mechanical circulatory support and 31 participants who did not require support	Trail Making Test A and B, Wisconsin Card Sorting Test	Presence of thrombus in assist device	Participants with thrombus had poorer scores on the Trail Making Test than the other two groups, participants with thrombus had a greater number of perseverative errors in the card sorting test than the other two groups	No difference in scores between mechanical support without thrombus group and the non support group.	No baseline data obtained. Participants had been on support for a mean of 4.1 years.

Patterns of Impairment

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Pressler, Subramanian, Kareken, Perkins, Gradus-Pizlo, Sauve, . . . Perkins (2010)	414 participants, 249 with heart failure, 63 healthy controls and 102 with other medical diseases	Charlson comorbidity Index, Patient Health Questionnaire, MMSE, Wechsler Test of Adult Reading, Boston Naming Test, Digit Span, Hopkins Verbal Learning Test, Figure Copy and Figure Memory Recall, Digit Symbol, Trail Making Test A and B, Controlled Oral Word Association	Blood pressure, educational level, gender, NYHA class	Significantly more heart failure patients were impaired in ≥ 3 domains. NYHA class was related to increased cognitive deficits. Men with HF had worse memory, psychomotor speed and visuospatial ability.	There was no difference in MMSE scores, Boston Naming test scores, Digit Span, Figure Copy and Figure Memory scores, and Controlled Oral Word Association Test score between groups.	Groups were not age matched.

Patterns of Impairment

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Putzke, Williams, Daniel, Foley, Kirklin, & Boll (2000)	44 subjects undergoing evaluation for cardiac transplantation and 44 gender, race, education and age range matched controls	Shipley Institute of Living Scale, Grooved Peg Board, Trail Making A and B, Weschler Memory Scale, Logical Memory Subtest, Wide Range Achievement Test	Hemodynamic measures including right atrial pressure, pulmonary artery pressure, pulmonary artery wedge pressure, cardiac output, cardiac index, systemic vascular resistance	Transplant group exhibited less motor speed and dexterity, but there was no significant difference in immediate and delayed memory tasks between groups.	As reported in results	Sample of cardiac transplant candidates limits generalizability to heart failure population.

Patterns of Impairment

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Putzke, Williams, Millsaps, Azrin, LaMarche, Bourge, Kirklin, McGiffin & Boll (1997)	760 candidates for cardiac transplantation who underwent extensive neuropsychological testing	See above	Age, gender, race, education, marital status, cardiac diagnosis	Subjects performed poorly most often in areas of manual speed, psychomotor speed, mental speed, and verbal learning and memory. Females performed better on verbal memory tests but less well on naming and motor dexterity.	As reported in results	Sample of cardiac transplant candidates limits generalizability to heart failure population.

Patterns of Impairment

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Sauve & Bennet (1999)	17 subjects with heart failure.	"Memory outcomes"	Age, left ventricular ejection fraction, New York Heart Functional Class,	Association between ejection fraction and early recall ($r=-.65$, $p=0.02$) and ejection fraction and recognition ($r=-.55$, $p=0.03$)	None reported	Small sample, cognitive tests not articulated

Patterns of Impairment

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Schall, Petrucci, Brozena, Cararocchi, & Jessup (1989)	54 subjects referred for cardiac transplantation, 20 of which participated in post operative testing.	Weschler Adult Intelligence Scale, Weschler Memory Scale, Halsted-Reitan neuropsychological battery,		22% of subjects awaiting transplant scored in the mildly impaired range and 56 in the moderately to severely impaired range for memory. For the Halsted-Reitan battery, 35% scored in the mildly impaired range and 39% in the moderately to severely impaired range.	No association with cause of heart failure or age,	Sample of cardiac transplant candidates limits generalizability to heart failure population. Small number of transplanted subjects limits ability to draw conclusions

Patterns of Impairment

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Trojano, Incalzi, Acanfora, Picone, Mecocci & Rengo (2003)	515 elderly hospitalized patients, 207 without congestive heart failure, 149 with moderate congestive heart failure and 159 with severe congestive heart failure. Moderate CHF subjects had New York Heart functional class II symptoms, CHF severe group had class III or IV symptoms.	MMSE, Attentional Matrices, Raven's Coloured Matrices, Categorical Verbal Fluency, Corsi Block Tapping, Rey's Immediate and Delayed Recall	New York Heart Class, age, gender, smoking and alcohol consumption history, BMI, cormorbidities,	Significant difference in MMSE scores between those without CHF and those with severe CHF. CHF participants were impaired in memory and attention.	Atrial fibrillation, alcohol use, respiratory diseases, and diabetes not associated with abnormal performance on three or more tests.	Hospitalized subjects may limit generalizabilty, other factors may inflence cognitive status

Patterns of Impairment

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Wolfe, Worrall-Carter, Foister, Keks, Howe (2006)	38 participants with heart failure recruited from one of two hospitals in Australia	Repeatable Battery for the Assessment of Neurological Status, Wisconsin Card Sort, Weschler Abbreviated Scale of Intelligence	Ejection fraction	RBANS total scale scores decreased in HF, as were immediate memory, delay memory and visuospatial/construction subscale scores compared to age related norms. Increased number of errors noted for WCST.	Ejection fraction did not correlate with cognitive performance	Small sample of hospitalized participants limits generalizability

Patterns of Impairment

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Zuccala, Cattel, Manes-Gravina, Di Niro, Cocchi, Bernabei (1997)	57 individuals with chronic heart failure admitted to hospital.	MMSE and Mental Deterioration Battery	CES-D, Barthel Activities for Daily Living (Katz's modification), blood chemistry, doppler echocardiography, New York Heart class.	MMSE scores <24 detected in 53% of subjects. Deficits noted in attention and complex reasoning.	Female gender, New York Heart Association class, hemoglobin, serum sodium and potassium, cholesterol, albumin and systolic blood pressure	Small sample of hospitalized participants limits generalizability

Demographics

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Cacciatore, Abete, Ferrara, Calabrese, Napoli, Maggi, Varricchio & Rengo (1998)	1339 elderly subjects from voter registration lists in Italy.	MMSE	Sex, age, marital status, educational level, Geriatric Depression Scale, New York Heart Classification, blood pressure	Subjects with MMSE score < 24 were more likely to have congestive heart failure than those who did not. They were also older and had higher GDS scores. Logistic regression analysis revealed that female gender, age, score on GDS, diastolic blood pressure, and the presence of congestive heart failure predicted cognitive impairment.	Systolic blood pressure, heart rate, drug therapy, diabetes, hypertension, alcohol consumption, smoking, atrial fibrillation.	MMSE has limited ability to detect mild cognitive impairment, according to some researchers, limited ability to detect memory impairment. Italian sample not generalizable to the Americas.

Demographics

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Reigel, Bennett, Davis, Carlson, Montague, Robin & Glaser (2002)	42 individuals with heart failure	MMSE, Boston Diagnostic Aphasia Examination Commands Subtest, Boston Diagnostic Aphasia Examination Complex Ideational Materials Subtest, Draw a Clock	Serum osmolality, age, blood pressure, education	31% of subjects scored in the impaired range in at least one of four tests using raw scores and 28.6% using T scores. None of the proposed correlates were significantly correlated with performance on cognitive measures. If MMSE used alone, only 2.4% of subjects would have been identified as impaired.	Age, educational level, serum osmolality and blood pressure	Small sample, curious choice of cognitive tests, limited ability to measure memory impairment

Demographics

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Sabatini, Barbisoni, Rozzini & Trabucchi (2002)	119 hospitalized patients with congestive heart failiure	MMSE	EKG, Echocardiography, Global Depression Scale, Charlson Comorbidity Index, APACHE score, serum albumin levels	Patients with evidence of cognitive impairment were older, had more comorbidity and increased APACHE scores, were more depression and had lower serum albumin levels. Reduced stroke volume and lower end-diastolic volume were also noted in those subjects scoring in the impaired range on MMSE.	Medications used, left ventricular mass index and left ventricular ejection fraction	Hospitalized subjects may limit generalizabilty, other factors may inflence cognitive status

Demographics

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Zuccala, Cattel, Manes-Gravina, Di Niro, Cocchi, Bernabei (1997)	57 individuals with chronic heart failure admitted to hospital.	MMSE and Mental Deterioration Battery	As above	MMSE scores <24 detected in 53% of subjects. Lower MMSE scores correlated with increased age. In final logistic regression analysis age and left ventricular ejection fraction predicted lower MMSE scores.	Female gender, New York Heart Association class, hemoglobin, serum sodium and potassium, cholesterol, albumin and systolic blood pressure	Small sample, hospitalized subjects may limit generalizability, other factors may influence cognitive status

Demographics

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Zuccala, Marzetti, Cesari, LoMonaco, Antonica, Cocchi, Carbonin, Bernabei (2005)	1,511 patients with CHF admitted to one of 81 hospitals in Italy enrolled in larger pharmacoepidemiologic study	Hodkinson Abbreviated Mental Test (AMT)	Charlson Comorbidity Index, age, gender, education, medications, lab work.	Patients with cognitive impairment were more likely to be older, female, and have less education than those not impaired.	Atrial fibrillation, hepatic disease, renal disease, dosed with digitalis, diuretics, antiplatelet and anticoagulant drugs, serum potassium	Retrospective analysis of large database. Hospitalized subjects may influence results. Italian population, hospitalized sample limits generalizability.

Demographics

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Zuccala, Onder, Pedone, Carosella, Pahor, Bernabei & Cocchi (2001)	1,583 subjects with heart failure enrolled in pharmacoepidemiologic study, 12,052 subjects without heart failure in same larger study	Hodkinson Abbreviated Mental Test (AMT)	Demographic and physiologic variables, blood pressure	In age and gender adjusted logistic regression model, SBP <130, age, female gender still significant predictors of cognitive impairment. SBP means, with CI 129, without CI 137 in heart failure group.	Presence of diabetes, renal disease, chronic pulmonary disease, atrial fibrillation, digitalis or diuretic use, serum sodium, potassium and creatinine.	Retrospective analysis of large database. Hospitalized subjects may influence results. Italian population, hospitalized sample limits generalizability.

Demographics

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Zuccala, Pedone, Cesari, Onder, Pahor, Marzetti, LoMonaco, Cocchi, Carbonin & Bernabei (2003)	1113 patients with heart failure admitted to one of 81 hospitals in Italy. 968 patients were followed for one year mortality that were enrolled in another study	Hodkinson Abbreviated Mental Test (AMT)	Comorbidities, medications, and deaths.	Those with cognitive impairment were more likely to be female, older and have less education, lower serum sodium, albumin, hemoglobin and lower blood pressure.	History of hypertension, diabetes, renal disease, atrial fibrillation, comorbidity score, use of digitalis, diuretics, spironolactone, warfarin, serum potassium, serum creatinine not associated with impairment.	Retrospective analysis of large database. Hospitalized subjects may influence results. Italian population, hospitalized sample limits generalizability.

New York Heart Association Class

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Callegari, Majani, Giardini, Pierobon, Opasich, Cobelli & Tavazzi (2002)	64 patients admitted to the hospital with heart failure exacerbation	Weschler Adult Intelligence Scale, Spinnler and Tognoni Battery	Cardiopulmonary artery exercise testing, right heart catheterization values, ejection fraction as measured by echocardiogram	New York Heart Association functional class did not correlate to any cognitive test score.		Small sample, hospitalized subjects limits generalizabilty.

New York Heart Association Class

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Gorkin, Norvel, Rosen, Charles, Shumaker, McIntyre, Capone, Kostis, Niaura, Woods, Hosking, Garces, Handberg, Ahern & Follick (1993)	318 subjects, 158 New York Heart Association class 1, 150 New York Heart Association Class 2 or 3.	Digit Span, Trail Making, Vocabulary	Demographic variables, risk factors, severity of disease, ejection fraction, medications, Functional status scale, consisting of six minute walk test, Functional Status scale, and Dyspnea Scale	Cognitive function scores did not correlate well with functional status scores. New York Heart Classification did not correlate with Vocabulary or Trail Making B, on the other hand, New York Heart Class 1 subjects performed better on Digit Span and Trail A than Class 2 or 3 subjects.	As reported in results	

New York Heart Association Class

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Incalzi, Trojano, Acanfora, Crisci, Tarantino, Abete & Rengo (2003)	369 subjects with stable heart failure already enrolled in CHF Italian Study	See above	BADL's, IADL's, GDS, NYHA class	As NYHA class increased, performance on recency, immediate recall, delayed recall and learning declined.	Etiology.	Secondary study, Italian cohort limits generalizability
Sauve & Bennett (2000)	30 subjects with heart failure	Variety of neuropsychological tests and scales measuring depression and adherence	Age, New York Heart Association class, ejection fraction	Cognitive impairment was not associated with New York Heart Association Class	Ejection fraction, emotional status or medication compliance	Small sample, cognitive tests and scales not articulated

New York Heart Association Class

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Trojano, Incalzi, Acanfora, Picone, Mecocci & Rengo (2003)	515 elderly hospitalized patients, 207 without congestive heart failure, 149 with moderate congestive heart failure and 159 with severe congestive heart failure. Moderate CHF subjects had New York Heart functional class II symptoms, CHF severe group had class III or IV symptoms.	MMSE, Attentional Matrices, Raven's Coloured Matrices, Categorical Verbal Fluency, Corsi Block Tapping, Rey's Immediate and Delayed Recall	New York Heart Class, age, gender, smoking and alcohol consumption history, BMI, cormorbidities,	Significant difference in MMSE scores between those without CHF and those with severe CHF. CHF severe subjects also scored worse than no CHF subjects in attention matrices and Rey's immediate and delayed recall. As heart failure severity increased, so did the number of abnormal scores, significant between the no CHF and CHF severe groups.	Atrial fibrillation, alcohol use, respiratory diseases, and diabetes not associated with abnormal performance on three or more tests.	Use of hospitalized subjects limits generalizability

Ejection Fraction

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Almeida & Tamai (2001)	50 consecutive patients admitted to emergency room with heart failure and 30 elderly controls without heart	Cambridge Examination for Mental Disorders, MMSE, Trail A & B, Digit Span, Digit Symbol, Letter Cancellation Test	See above	Cognitive scores were associated with ejection fraction.	None reported	Recruitment of participants from the emergency room limits generalizability
Bornstein, Starling, Myerowitz & Haas (1995)	See above	See above	Right atrial pressure, left ventricular ejection fraction, pulmonary artery wedge pressure, Cardiac Index, Stroke/volume Index	See above	Impairment Index with pulmonary artery pressure, cardiac index, stroke volume/stroke volume index and ejection fraction	Sample of cardiac transplant candidates not representative of heart failure population, limited number that were transplanted further limits ability to make conclusions.

Ejection Fraction

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Callegari, Majani, Giardini, Pierobon, Opasich, Cobelli & Tavazzi (2002)	64 patients admitted to the hospital with heart failure exacerbation	Weschler Adult Intelligence Scale, Spinnler and Tognoni Battery	See Above	Ejection fraction as measured by echocardiogram did not correlate to any cognitive test score.		Small sample, hospitalized subjects limits generalizabilty.
Sabatini, Barbisoni, Rozzini & Trabucchi (2002)	119 hospitalized patients with congestive heart failiure	MMSE	See Above	See above	Medications used, left ventricular mass index and left ventricular ejection fraction	Hospitalized subjects may limit generalizabilty, other factors may inflence cognitive status
Sauve & Bennet (1999)	17 subjects with heart failure.	"Memory outcomes"	Age, left ventricular ejection fraction, New York Heart Functional Class,	Association between ejection fraction and early recall ($r=-.65$, $p=0.02$) and ejection fraction and recognition ($r=-.55$, $p=0.03$)	None reported	Small sample, cognitive tests and scales not articulated

Ejection Fraction

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Sauve & Bennett (2000)	30 subjects with heart failure	Variety of neuropsychological tests and scales measuring depression and adherence	Age, New York Heart Association class, ejection fraction	Cognitive impairment was not associated with ejection fraction	New York Heart Association class, emotional status or medication compliance	Small sample, cognitive tests and scales not articulated

Physiological Variables

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Beer, Ebenezer, Fenner, Lautenschlager, Flicker & Almeida (2009)	31 participants with heart failure and 24 healthy controls	Cambridge Examination for Mental Disorders of the Elderly	MRI brain imaging, six minute walk, serum aldosterone levels, serum cortisol levels, serum renin levels	Participants with heart failure had poorer CAMCOG scores. Aldosterone levels were higher in heart failure participants. There was more right medial temporal lobe atrophy in heart failure participants.		Small sample size
Reigel, Bennett, Davis, Carlson, Montague, Robin & Glaser (2002)	42 individuals with heart failure	As Above	Serum osmolality, age, blood pressure, education	As Above	Age, educational level, serum osmolality and blood pressure	Small sample, curious choice of cognitive tests, limited ability to measure memory impairment

Physiological Variables

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Zuccala, Marzetti, Cesari, LoMonaco, Antonica, Cocchi, Carbonin & Bernabei (2005)	1,511 patients with CHF admitted to one of 81 hospitals in Italy enrolled in larger study	Hodkinson Abbreviated Mental Test (AMT)	Charlson Comorbidity Index, age, gender, education, medications, lab work.	Patients with cognitive impairment were more likely to have coronary artery disease, hypertension, higher comorbidity score, be on ACE inhibitors, beta blockers, nitrates, have higher serum sodium, creatinine, and lower albumin, hemoglobin and	Atrial fibrillation, hepatic disease, renal disease, dosed with digitalis, diuretics, antiplatelet and anticoagulant drugs, serum potassium	Retrospective analysis of large database. Hospitalized subjects may influence results. Italian population, hospitalized sample limits generalizability .

Physiological Variables

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Zuccala, Onder, Pedone, Carosella, Pahor, Bernabei & Cocchi (2001)	1,583 subjects with heart failure enrolled in pharmacoepidemiologic study, 12,052 subjects without heart failure in same larger study	Hodkinson Abbreviated Mental Test (AMT)	Demographic and physiologic variables, blood pressure	Systolic blood pressure < 130 in subjects with CHF increased likelihood of cognitive impairment, not in those without CHF. In age and gender adjusted logistic regression model, SBP <130, age, female gender still significant predictors of cognitive impairment. SBP means, with CI 129, without CI 137 in heart failure group.	Presence of diabetes, renal disease, chronic pulmonary disease, atrial fibrillation, digitalis or diuretic use, serum sodium, potassium and creatinine.	Retrospective analysis of large database. Hospitalized subjects may influence results. Italian population, hospitalized sample limits generalizability.

Effects of Medications

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Tzourio, et al (2003)	6105 participants with previous stroke or transient ischemic attack, randomized to receive perindopril or placebo.	Mini Mental Status Examination	Evidence of cognitive decline as measured by MMSE compared to administration of perindopril	Over the 3.9 year study period, risk of cognitive decline decreased with administration of perindopril (p=.01)		Not tested in heart failure population, perindopril not approved for use in heart failure in US.

Effects of Medications

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Zuccala, Onder, Marzetti, LoMonaco, Cesari, Cocchi, Carbonin, Bernabei (2005)	1220 patients with heart failure not on ACE inhibitor enrolled in pharmacopeidemiologic study. Larger study 17,526 patients admitted to hospital	Hodkinson Abbreviated Mental Test (AMT)	Addition of ACE inhibitor, comorbidities, serum chemistries, blood pressure	CI present at baseline in 34% of subjects with systolic blood pressure ≥ 130 , and 45% of those with systolic blood pressure <130 (0.001). AMT scores improved in 30% of patients started on ACE inhibitors and 22% of those not started on ACE inhibitors	Comorbid conditions, coronary artery disease, hypertension, diabetes, anemia, renal disease, hepatic disease, serum sodium, potassium and creatinine	Retrospective analysis of large database, difficult to infer causality. Italian cohort, not generalizable.

Disability, mortality, readmissions and compliance

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Rozzini, Sabatini & Trabucchi (2004)	1092 elderly patients,	MMSE	6 month mortality, Charlson Comorbidity Index, seum albumin, disability in ADL's and APACHE score	Mortality for entire group 11%, those without heart failure or cognitive impairment mortality was 5.7%, with heart failure and no cognitive impairment, 19%, with cognitive impairment and no heart failure 31%, and in those with both heart failure and cognitive impairment, 35.6%.	Not reported.	

Disability, mortality, readmissions and compliance

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Sauve & Bennet (2000)	30 subjects with heart failure.	Neuropsychological tests and tools measuring emotions, symptoms and adherence	Cognitive tests, depression scores, adherence self report, age, ejection fraction and New York Heart Association Class	Memory impairments were not related to self reported medication adherence,	Age, ejection fraction and New York Heart Association Class	Small sample, cognitive tests not articulated.

Disability, mortality, readmissions and compliance

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Schwarz & Elman (2003)	156 patient caregiver dyads, 128 of which completed the study	MMSE	NYHA class, perceived stress scores, Index if ADL's, IADL's, severity of illness,	44% readmitted to hospital within three months. There was no difference between those readmitted and those not readmitted in any variable. Subjects who did not complete study had poorer cognition and lower functional class than those who finished the study.	As reported in results	Lack of outcome data on those who did not complete the study.

Disability, mortality, readmissions and compliance

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Zuccala, Onder, Pedone, Cocchi, Carosella, Cattel, Carbonin & Bernabei (2001)	1583 individuals with heart failure and without cerebrovascular disease, stroke or Alzheimers disease. These subjects were admitted to one of 81 hospitals and were enrolled in a larger pharmacoepidemiological study	Hodkinson Abbreviated Mental Test (AMT)	Activities of Daily Living Scale (Katz version), demographics, medications and comorbidities	Cognitive dysfunction was present in 265/461 disabled subjects, and in 150/1122 subjects without disability (p<.0001). Cognitive dysfunction was predictive of disability in regression analysis (OR=8.69)	Gender, diabetes, renal disease, atrial fibrillation, serum sodium, potassium or creatinine, use of calcium antagonists, diuretics, digitalis, nitrates or antiaggregants not associated with disability.	Retrospective analysis of large database. Hospitalized subjects may influence results. Italian population, hospitalized sample limits generalizability.

Disability, mortality, readmissions and compliance

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Zuccala, Pedone, Cesari, Onder, Pahor, Marzetti, LoMonaco, Cocchi, Carbonin & Bernabei (2003)	1113 patients with heart failure admitted to one of 81 hospitals in Italy. 968 patients were followed for one year mortality that were enrolled in another study	Hodkinson Abbreviated Mental Test (AMT)	Comorbidities, medications, and deaths.	Subjects with cognitive impairment had increased one year mortality at 27% versus those without cognitive impairment at 15% (p<.0001). Cognitive impairment also predicted in hospital mortality in Cox regression models (RR 4.9%), systolic or diastolic blood pressure not significant predictor	History of hypertension, diabetes, renal disease, atrial fibrillation, comorbidity score, use of digitalis, diuretics, spironolactone, warfarin, serum potassium, serum creatinine not associated with impairment.	Retrospective analysis of large database. Hospitalized subjects may influence results. Italian population, hospitalized sample limits generalizability.

Symptom recognition

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Evangelista, Dracup & Doering, (2000)	753 subjects admitted to a Veteran's Administration Facility for HF	Retrospective chart review	Symptoms and duration of symptoms prior to seeking medical attention	Mean time to treatment seeking was 2.83 days. Most common symptoms were dyspnea, edema and fatigue.	Age, gender, marital status, living arrangement, and employment status did not affect delay	Retrospective review, presence of symptoms and duration dependent upon chart documentation and recall by subject.

Symptom recognition

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Friedman (1997)	181 subjects admitted to an acute care hospital	Retrospective chart review	Symptom history, medical history, social and demographic variables	Most common symptom was dyspnea, followed by acute dyspnea, edema and cough. Shortness of breath was present 3 days before treatment seeking, acute dyspnea 12 hours and edema for 7 days. Patients with a history of heart failure tended to wait longer	Age was not related to symptom duration as a whole.	Retrospective review, presence of symptoms and duration dependent upon chart documentation and recall by subject.

Symptom recognition

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Hou, Bennett, Eckert, Deer, Embree, Browning, Chui & Murray (2000)	145 participants with HF recruited for larger study from the outpatient clinics	Short Portable Mental Status Questionnaire, Chronic Heart Failure Questionnaire	Gender, age, race, education, New York Heart Association Class, and comorbidity	Lower education, African American race and less reported dyspnea symptoms were correlated to cognitive status.	Age, New York Heart Classification, gender.	One screening test for cognitive impairment used.

Cardiac Transplant Candidates

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Bornstein, Starling, Myerowitz & Haas (1995)	62 subjects with end stage congestive heart failure undergoing cardiac transplant evaluation. Of these 62, seven transplanted and four non transplanted subjects were retested	Neuropsychological battery consisting of Weschler Adult Intelligence Scale-Revised, Logical Memory and Visual Reproduction tests, Verbal Concept Attainment Test, Wisconsin Card Sort, Trail Making A and B, COWA, Grooved Pegboard Test, Finger Tapping Test, Seashore Rhythm Test, Speed Perception Test, Digit Span and Knox Cube Tests.	Right atrial pressure, left ventricular ejection fraction, pulmonary artery wedge pressure, Cardiac Index, Stroke/volume Index	Subjects overall scores were in the impaired range in over 50% of measures. Sum scores indicate that 58% of subjects scored in the impaired range on 45% or more of the tests. After transplant, subjects attained an improvement in mean scores of 11%, compared to no improvement in those not transplanted.	Impairment Index with pulmonary artery pressure, cardiac index, stroke volume/stroke volume index and ejection fraction	Sample of cardiac transplant candidates not representative of heart failure population, limited number that were transplanted further limits ability to make conclusions.

Cardiac Transplant Candidates

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Grimm, Yeganehfar, Laufer, Madl, Kramer, Eisenhuber, Simon, Kupilik, Schreiner, Pacher, Bunzell, Wolner & Grimm (1996)	55 consecutive cardiac transplant candidates, 30 of which were transplanted. Of the 30 transplanted, 25 were studied after transplantation	MMSE, Trail Making A	Profile of Mood States, Cognitive P300 evoked potentials	Trail Making A times were significantly slower in the transplant candidate group than in controls ($p<.01$). MMSE scores were not significantly different than controls. MMSE scores did improve, however, after transplant ($p<.05$), and Trail A scores improved, but not significantly. P300 potentials were prolonged at baseline as compared to controls ($p<.01$)	P 300 potentials improved at 4 months and declined again at 12 months after transplant	Sample of cardiac transplant candidates not representative of heart failure population, limited number that were transplanted further limits ability to make conclusions.

Cardiac Transplant Candidates

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Gruhn, Larsen, Boesgaard, Knudsen, Mortensen, Thomsen & Aldershvile (2001)	12 patients evaluated for cardiac transplantation. 11 were men. Five of the 12 were subsequently transplanted in the next six months. 12 age matched healthy controls for comparison.	Cerebral blood flow as measured by single-photon emission computed tomography with a Xenon 133 tracer, and middle cerebral artery velocity as measured by transcranial ultrasound.	New York Heart Functional Class, demographic data, blood pressure	Resting cerebral blood flow was 31% lower in the group with congestive heart failure. Cerebral blood flow increased after transplant, to 50 ml/min ($p < .05$), which was comparable to controls. Middle cerebral artery velocities by doppler were decreased compared to controls, but not significantly.	No localization, trend toward decreased blood flow in middle cerebral artery, but not significant. Similarly, middle cerebral artery flows did not increase significantly after transplant	Sample of cardiac transplant candidates not representative of heart failure population, limited number that were transplanted further limits ability to make conclusions.

Cardiac Transplant Candidates

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Putzke, Williams, Daniel, Foley, Kirklin, & Boll (2000)	44 subjects undergoing evaluation for cardiac transplantation and 44 gender, race, education and age range matched controls	Shipley Institute of Living Scale, Grooved Peg Board, Trail Making A and B, Weschler Memory Scale, Logical Memory Subtest, Wide Range Achievement Test	Hemodynamic measures including right atrial pressure, pulmonary artery pressure, pulmonary artery wedge pressure, cardiac output, cardiac index, systemic vascular resistance,	Transplant group exhibited less motor speed and dexterity, but there was no significant difference in immediate and delayed memory tasks between groups.	As reported in results	Sample of cardiac transplant candidates not representative of heart failure population.

Cardiac Transplant Candidates

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Putzke, Williams, Millsaps, Azrin, LaMarche, Bourge, Kirklin, McGiffin & Boll (1997)	760 candidates for cardiac transplantation who underwent extensive neuropsychological testing	Shipley Institute of Living Scale, Weschler Adult Intelligence Scale, Boston Naming Test, COWAT, Grooved Peg Board Test, Trail Making A and B, Symbol Digit Modalities Test, Stroop Neuropsychological Screening Test, Weschler's Memory Scale-Russell's revision, Visual Reproduction Test, Selective Reminding Test, Paried Associate Subtest of Weschler Memory Scale	Age, gender, race, education, marital status, cardiac diagnosis	77% of subjects had one or more test and 35% had five or more scores in the impaired range. Subjects scored poorly most often in areas of manual, psychomotor, mental speed, and verbal learning and memory. Younger age and more years of education were associated with better scores.	As reported in results	Sample of cardiac transplant candidates not representative of heart failure population.

Cardiac Transplant Candidates

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Putzke, Williams, Millsaps, Azrin, LaMarche, Bourge, Kirklin, McGiffin & Boll (1997) (con't)				Females performed better on verbal memory tests but less well on naming and motor dexterity. Those with greater years of education performed better on all tests except those of motor dexterity.		

Cardiac Transplant Candidates

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Schall, Petrucci, Brozena, Cararocchi, & Jessup (1989)	54 subjects referred for cardiac transplantation, 20 of which participated in post operative testing.	Weschler Adult Intelligence Scale, Weschler Memory Scale, Halsted-Reitan neuropsychological battery,		22% of subjects scored in the mildly impaired range and 56 in the moderately to severely impaired range for memory. For the Halsted-Reitan battery, 35% scored in the mildly impaired range and 39% in the moderately to severely impaired range.	No association with cause of heart failure or age,	Sample of cardiac transplant candidates not representative of heart failure population, limited number that were transplanted further limits ability to make conclusions.

Cardiac Transplant Candidates

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Schall, Petrucci, Brozena, Cararocchi, & Jessup (1989) (con't)				For those who completed both series of tests, full scale IQ, speech sounds perception and finger oscillation subtests of the Halsted-Reitan battery were improved, however, not significantly.		

Nursing Investigations

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Bennett, Cordes & Westmoreland (2000)	23 participants with HF and 18 family members	Focous group technique, 6 with the HF participants, 6 with the family members		Participants reported physical and emotional symptoms, including shortness of breath, swelling, and symptoms related to diuretic therapy. 5 out of the six groups reported difficulty in concentration. In the group that did not report this difficulty, the family members reported its presence		

Nursing Investigations

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Europe & Tynni- lenne (2004)	20 males with NYHA class II or III heart failure	Qualitative interview		Two themes emerged, consequences of illness and adjustment to illness. One consequence felt to be decreased memory function and difficulty in concentration.		

Nursing Investigations

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Ekman, Fagerberg, Skoog (2001)	157 subjects with chronic congestive heart failure.	MMSE	Age, gender, duration of heart failure, hemoglobin, creatinine clearance,	Cognitive impairment was associated with duration of heart failure and lower hemoglobin in logistic regression analysis. Subjects with cognitive impairment at baseline more likely to be nonparticipants in nurse managed heart failure program.	Gender, history of hypertension, stroke, or myocardial infarction, New York Heart Functional Class, ejection fraction, or systolic blood pressure	

Nursing Investigations

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Karlson, Edner, Henriksson, Mejhert, Persson, Grut & Billing (2005)	208 hospitalized subjects with heart failure randomized to standard care vs nurse managed followup program	MMSE	Knowledge questionnaire consisting of 33 questions,	No difference in knowledge level after six months in either control or intervention group. However, individuals with MMSE score <24 had lower knowledge scores at baseline. This difference disappeared at six months. 12% of individuals had MMSE score <24 at baseline, compared to 4% after six months.	As reported in results	

Nursing Investigations

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Reigel, Bennett, Davis, Carlson, Montague, Robin & Glaser (2002)	42 individuals with heart failure	MMSE, Boston Diagnostic Aphasia Examination Commands Subtest, Boston Diagnostic Aphasia Examination Complex Ideational Materials Subtest, Draw a Clock	Serum osmolality, age, blood pressure, education	31% of subjects scored in the impaired range in at least one of four tests using raw scores and 28.6% using T scores. None of the proposed correlates were significantly correlated with performance on cognitive measures. If MMSE used alone, only 2.4% of subjects would have been identified as impaired.	Age, educational level, serum osmolality and blood pressure	

Nursing Investigations

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Schwarz & Elman (2003)	156 patient caregiver dyads, 128 of which completed the study	MMSE	NYHA class, perceived stress scores, Index of ADL's, IADL's, severity of illness,	44% readmitted to hospital within three months. There was no difference between those readmitted and those not readmitted in any variable. Subjects who did not complete study had poorer cognition and lower functional class than those who finished the study.	As reported in results	

Nursing Investigations

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Sloan & Pressler (2009)	12 Participants known to be cognitively impaired	Intrepretive phenomonology		Participants described two themes, awareness of cognitive deficits and unawareness of cognitive deficits		

Effect of Medical Interventions

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Dixit, Vazquez, Cross, Kuhl, Serber, Kovacs, . . . Sears (2009)	20 participants assessed before and after bi-ventricular pacemaker placement	Digit Span, Trail Making A and B, Digit Symbol, Hopkins Verbal Learning Test, Controlled Oral Word Association, Center for Epidemiologic Studies Depression Scale, Minnesota Living with Heart Failure Questionnaire, Left Ventricular Dysfunction Questionnaire, State-Trait Anxiety Inventory	Age	Study group had significantly better scores on Digit Span, Digit Symbol, Controlled Oral Word Association, and quality of life	No difference in scores on Hopkins Verbal Learning Test, depression,	Relatively small sample, no physiological variables assessed.

Effect of Medical Interventions

<i>Author (year)</i>	<i>Sample</i>	<i>Tools</i>	<i>Variables</i>	<i>Results</i>	<i>Nonsignificant results</i>	<i>Limitations</i>
Hoth, Poppas, Ellison, Paul, Sokobin, Cho & Cohen (2010)	27 participant with heart failure who underwent bi-ventricular pacemaker placement	Repeatable Battery for the Assessment of Neuropsychological Status, Trail Making A and B, Controlled Oral Word Association Test, Weschler Adult Intelligence Scale Letter Number Sequencing, Minnesota Living with Heart Failure Questionnaire, Beck Depression Inventory	Ejection fraction as measured by echocardiography, Six minute walk test,	Participants with improved ejection fraction after implant had improved scores in executive function and visuospatial domains. There was less global decline in those whose EF improved than those whose EF did not improve	No difference in RBANS scores, Trail Making Scores or Controlled Oral Word Association Tests	Relatively small sample.

APPENDIX B
SELF-CARE IN HEART FAILURE INDEX

SELF-CARE OF HEART FAILURE INDEX©

All answers are confidential

Date Completed_____

SECTION A:

Listed below are common recommendations for persons with heart failure. How often do you do the following?

	Never or rarely	Sometimes	Frequently	Always
1. Weigh yourself daily?		2	3	4
2. Eat a low salt diet?	1	2	3	4
3. Take part in regular physical activity?	1	2	3	4
4. Keep your weight down?	1	2	3	4
5. Get a flu shot every year?	1	2	3	4

SECTION B:

Many patients have symptoms due to their heart failure. Trouble breathing and ankle swelling are common symptoms of heart failure.

In the past three months, have you had trouble breathing or ankle swelling? Circle one.

- 1) No
- 2) Yes

6. The LAST TIME you had trouble breathing or ankle swelling.

(circle **one** number)

	I did not recognize it	Not Quickly	Somewhat Quickly	Quickly	Very Quickly
How quickly did you recognize it as a symptom of heart failure?	0	1	2	3	4

Listed below are remedies that people with heart failure use. When you have trouble breathing or ankle swelling, how likely are you to try one of these remedies?

(circle one number for each remedy)

	Not Likely	Somewhat likely	Likely	Very Likely
7. Reduce the salt in your diet?	1	2	3	4
8. Reduce your fluid intake?	1	2	3	4
9. Take an extra water pill?	1	2	3	4
10. Call your doctor or nurse for guidelines?	1	2	3	4

11. If you tried any of these remedies the last time you had trouble breathing or ankle swelling

(circle **one** number)

	I did not try anything	Not Sure	Somewhat Sure	Sure	Very Sure
How <u>sure</u> were you that the remedy helped or not?	N/A	1	2	3	4

SECTION C:

	Not Confident	Somewhat Confident	Very Confident	Extremely Confident
12. How confident are you that you can <u>evaluate the importance of</u> your symptoms?	1	2	3	4
13. Generally, how confident are you that you can <u>recognize changes</u> in your health if they occur?	1	2	3	4
14. Generally, how confident are you that you can <u>do something</u> that will relieve your symptoms?	1	2	3	4
15. How confident are you that you can <u>evaluate the effectiveness</u> of whatever you do to relieve your symptoms?	1	2	3	4

APPENDIX C

REPEATABLE BATTERY FOR THE ASSESSMENT OF
NEUROPSYCHOLOGICAL STATUS

Copyright holder of the Repeatable Battery for the Assessment of Neuropsychological Status does not allow reproduction of the test content. Please visit www.Pearson.com for details about the RBANS.

APPENDIX D

PSYCHOMETRIC PROPERTIES OF THE
REPEATABLE BATTERY FOR THE ASSESSMENT
OF NEUROPSYCHOLOGICAL STATUS

Type	Sample	Result	Author
Test-retest (one year)	455 elderly community based participants	Total scale $r=.82$ immediate memory $r=.70$ language $r=.58$ attention $r=.58$ delayed memory $r=.77$ visuospatial/constructional $r=.62$.	Duff, Beglinger et al. (2005)
Test-retest (12 weeks, alternate forms)	53 schizophrenic patients	Total scale $r=.84$ Immediate memory $r=.72$ Visuospatial/constructional $r=.68$ language $r=.51$ attention $r=.91$ delayed memory $r=.64$	Gold et al (1999)
Test-retest (6weeks)	181 patients with schizophrenia and 99 healthy controls	Schizophrenic: Total scale $r=.84$, immediate memory $r=.69$, visuospatial/constructional $r=.71$ language $r=.54$ attention $r=.81$ delayed memory $r=.69$. Healthy controls Total scale $r=.78$ immediate memory $r=.55$ visuospatial/constructional $r=.53$ language $r=.38$ attention $r=.77$ delayed memory $r=.57$	Wilk et al (2002)

Type	Sample	Result	Author
Internal consistency reliability	129 patients with schizophrenia	alpha=.88	Gold et al. (1999)
Internal consistency reliability	57 patients with moderate to severe brain injury	Immediate memory alpha=.75 Visuospatial/constructional alpha=.76 Language alpha=.32 Delayed memory alpha =.77 Attention alpha =.16 Total scale alpha =.84	McKay et al. (2007)
Internal consistency reliability	937 community dwelling elderly	alpha= .86	Gontkovsky, Beatty and Mold (2004)

Type	Sample	Result	Author
Construct validity	824 community dwelling elderly	<p>Neither a one factor or a five factor solution was supported in confirmatory factor analysis.</p> <p>Exploratory factor analysis supported a two factor solution.</p>	Duff, Langbehn et al. (2006)
Construct validity	210 patients with ischemic stroke	Exploratory factor analysis supported a two factor solution explaining 61% of the variance. Factors were language/verbal and visuospatial/visual memory	Wilde (2006)

Type	Sample	Result	Author
Criterion validity	158 patients with CVA hospitalized in inpatient rehabilitation facility	<p>Attention Index: TMT A $r = -.27$ ($p < .05$) TMT B $r = -.31$ ($p < .05$) Executive interview $r = -.37$ ($p < .05$)</p> <p>Language Index Boston Diagnostics Aphasia Exam Repetition $r = .42$ ($p < .001$) Boston Diagnostics Aphasia Exam Commands $r = .38$ ($p < .001$) Weschler Adult Intelligence Scale-Revised Vocabulary $r = .51$ ($p < .001$)</p> <p>Visuospatial/constructional index Ravens coloured progressive matrixes $r = .66$ ($p < .001$) Benton Faces $r = .40$ ($p < .001$)</p> <p>Immediate memory index Rivermead Behavioural Memory Test $r = .68$ ($p < .001$)</p> <p>Delayed memory index Rivermead Behavioural Memory Test $r = .72$ ($p < .001$)</p>	Larson et al. (2005).

Type	Sample	Result	Author
Criterion validity	210 patients with ischemic stroke	<p>Controlled Oral Word Association correlated with language/verbal memory factor ($r=.65$, $p<.001$)</p> <p>The Visual Form Discrimination Test with the visuospatial/visual memory factor ($r=.60$, $p=.001$)</p> <p>MMSE correlated significantly with both factors ($r=.52$, $p<.001$ for visuospatial/visual memory and $r=.57$, $p<.001$ for the language/verbal memory factors)</p>	Wilde (2006)

Type	Sample	Result	Author
Criterion validity	57 patients with moderate to severe brain injury	<p>List learning and story memory with CVLT $r=.695$ ($p<.01$) and $.420$ ($p<.05$)</p> <p>Figure copy with Benton Visual Retention Test errors, $r= -.317$ ($p<.05$)</p> <p>Line orientation with BVRT correct and errors, $r=.534$ ($p<.01$) $-.497$ ($p<.001$)</p> <p>Picture naming with Multilingual Aphasia Examination $r=.590$ ($p<.001$)</p> <p>Semantic fluency with Controlled Oral Word Association $r=.456$ ($p<.01$)</p> <p>Digit Span with WAIS-III digit span $r=.623$ ($p<.01$)</p> <p>Coding with WAIS-III Digit symbol coding $r=.827$ ($p<.01$)</p> <p>Delayed list recall with CVLT long delay recall $r=.753$ ($p<.01$)</p> <p>Delayed story recall with CVLT long delay recall $r=.705$ ($p<.01$)</p> <p>List recognition with CVLT recognition hits $r=.381$ ($p<.01$)</p> <p>Delayed figure recall with BVRT correct $r=.583$ ($p<.01$)</p>	McKay et al. (2007)

Type	Sample	Result	Author
Criterion validity	69 patients referred for neuropsychological testing	<p>RBANS figure copy with Rey Complex Figure Test Copy $r=.76$ ($p<.001$)</p> <p>RBANS figure recall with Rey Complex Figure Test Delayed Recall $r=.65$ ($p<.001$)</p> <p>RBANS list recall and Rey Auditory Verbal Learning Test $r=.65$ ($p<.001$)</p> <p>RBANS picture naming and Boston Naming Test $r=.71$ ($p<.001$)</p> <p>RBANS semantic fluency with Controlled Oral Word Association $r=.74$ ($p<.001$)</p>	Gontkovsky et al (2002)
Criterion validity	37 patients with acquired brain injury in long term rehabilitation facility	<p>Immediate memory with California Verbal Learning Test total $r=.72$ ($p<.005$), logical memory $r=.79$ ($p<.005$)</p> <p>Visuospatial/constructional with Rey Complex Figure Test immediate recall $r=.48$ ($p=.004$), RCFT delayed recall $r=.47$ ($p=.005$), TMT A/B $r=.39/.32$ ($p=.02/.07$), WAIS-III block design $r=.63$ ($p=.005$) Grooved Peg Board $r=.52$ ($p=.002$)</p> <p>Attention with WMS-III digit span $r=.63$ ($p=.005$). Delayed memory with CVLT long delay free recall $r=.69$ and CVLT recognition $r=.70$ ($p=.005$)</p>	Pachet et al. (2007)

Type	Sample	Result	Author
Criterion validity	27 patients with Parkinson's Disease	RBANS total and subscales scores correlated with MMSE Total $r=.756$, $p<.001$ Immediate memory $r=.552$, $p<.001$ Visuospatial/constructional $r=.674$, $p<.001$ Attention $r=.730$, $p<.001$ Delayed memory $r=.531$, $p<.01$	Ryder et al (2002)
Criterion validity	150 patients with various psychiatric disorders, 59 with schizophrenia, 42 with schizoaffective disorder, 29 with bipolar disorder, 12 with mood disorder and 9 other disorder	RBANS total scores correlated with Wechsler Adult Intelligence full scale $r=.75$ WAIS vocabulary $r=.64$ WAIS comprehension $r=.57$ WAIS block design $r=.62$ WAIS picture arrangement $r=.66$ WAIS letter-number sequencing $r=.62$ Wechsler Memory Scale Logical memory 1 $r=.68$ Logical memory 2 $r=.66$ Visual reproduction 1 $r=.58$ Visual reproduction 2 $r=.52$ All scores significant $p<.05$	Hobart et al (1999)

Type	Sample	Result	Author
Criterion validity	129 patients with schizophrenia	<p>Total scale with Weschler Adult Intelligence Scale-III $r=.77$ ($p<.001$)</p> <p>Weschler Memory Scale immediate memory $r=.67$ ($p<.001$), and general memory $r=.69$ ($p<.001$)</p> <p>Immediate memory subscale with working memory subscale of WAIS-III $r=.65$ ($p<.05$), with immediate memory $r=.69$ ($p<.001$), WMS general memory $r=.72$ ($p<.001$)</p> <p>Attention subscale with WAIS full scale $r=.73$ ($p<.001$) and working memory index $r=.81$ ($p<.001$).</p>	Gold et al. (1999)

Type	Sample	Result	Author
Concurrent validity	69 patients referred for neuropsychological evaluation	100% of patients that scored below 24 on MMSE scored below cut scores for impairment on RBANS	Gontkovsky et al (2002)
Concurrent validity	58 patients with multiple sclerosis	MS patients with MMSE scores less than 27 had lower total index scores ($p<.001$), lower list learning scores ($p<.01$), lower story memory scores ($p<.05$), and lower list recall ($p<.01$)	Beatty (2004)

Type	Sample	Result	Author
Discriminant validity	129 patients with schizophrenia	RBANS total and subscale scores with the exception of visuospatial/constructional discriminated between schizophrenic patients who were able to work and those who were not ($p < .05$), sensitivity .64 to .75	Gold et al (1999)
Discriminant validity	28 students grouped into 4 groups: nonathletes/nonconcussed, athlete/nonconcussed, athlete/non recently concussed, and athlete/recently concussed	<p>RBANS form A memory scores significantly differed between groups.</p> <p>Immediate memory in athlete/nonconcussed differed from nonathlete/nonconcussed ($p \leq .05$), athlete/recently concussed differed from nonathlete/nonconcussed ($p \leq .05$) and from athlete/nonrecently concussed ($p \leq .05$)</p> <p>Delayed memory in athlete/nonconcussed differed from nonathlete/nonconcussed ($p \leq .01$), athlete/recently concussed differed from nonathlete/nonconcussed ($p \leq .05$)</p>	Killam et al (2005)

Type	Sample	Result	Author
Discriminant validity	80 participants, 20 with Alzheimer's disease (AD), 20 with Huntington's disease (HD), 20 young normal controls (YNC) and 20 old normal controls (ONC)	<p>Immediate memory</p> <p>YNC differed from ONC, HD and AD</p> <p>HD and AD did not differ from each other</p> <p>ONC and YNC differed</p> <p>Visuospatial/constructional</p> <p>YNC, ONC and AD did not differ</p> <p>HD differed from YNC, ONC and AD</p> <p>Language</p> <p>YNC differed from HD and AD</p> <p>ONC differed from HD and AD</p> <p>ONC and YND did not differ</p> <p>HD differed from AD</p> <p>Attention</p> <p>YNC and ONC did not differ</p> <p>YNC and ONC differed from AD and HD</p> <p>HD differed from AD</p> <p>Delayed Memory</p> <p>YNC and ONC did not differ</p> <p>YNC and ONC differed from HD and AD</p> <p>AD differed from HD</p>	Randolf et al (1998)

Type	Sample	Result	Author
Predictive validity	70 patients with stroke reassessed after 12 months	RBANS score correlated with scores on the Cognitive Factor of the Functional Independence Measure ($r=.48$ for attention, $.61$ for immediate memory, $.63$ for delayed memory and visuospatial/constructional and $.72$ for total scale)	Larson et al (2005)

APPENDIX E

PATIENT AND CAREGIVER FORMS OF THE
ANOSOGNOSIA QUESTIONNAIRE-DEMENTIA

Patient Form**Study ID:** _____ **Date:** _____

These questions ask about behaviors and thinking problems that some people experience. For each question, circle how often you notice the behavior in yourself.

1. How often do you have problems remembering the date?
never sometimes often always
2. How often do you have problems orienting yourself in new places?
never sometimes often always
3. How often do you have problems remembering telephone conversations?
never sometimes often always
4. How often do you have problems understanding conversations?
never sometimes often always
5. How often do you have problems signing your signature?
never sometimes often always
6. How often do you have problems understanding what you read in the newspaper?
never sometimes often always
7. How often do you have problems keeping your personal belongings in order?
never sometimes often always
8. How often do you have problems remembering where you leave things in your house?
never sometimes often always
9. How often do you have problems writing notes or letters?
never sometimes often always

10. How often do you have problems handling money?
never sometimes often always
11. How often do you have problems orienting yourself in your neighborhood?
never sometimes often always
12. How often do you have problems remembering your appointments?
never sometimes often always
13. How often do you have problems doing your favorite hobbies?
never sometimes often always
14. How often do you have problems communicating with people?
never sometimes often always
15. How often do you have problems performing mental calculations?
never sometimes often always
16. How often do you have problems remembering things you have to buy when you go shopping?
never sometimes often always
17. How often do you have problems controlling your sphincters? (i.e. movement of urine and stool)
never sometimes often always
18. How often do you have problems understanding the plot of a movie?
never sometimes often always
19. How often do you have problems orienting yourself in your house?
never sometimes often always

20. How often do you have problems performing household activities (cooking, cleaning fixing things, etc?)
never sometimes often always
21. How often do you have problems feeding yourself?
never sometimes often always
22. How often do you have problems keeping your checkbook, accounts, payments, etc?
never sometimes often always
23. How often are you more rigid in your decisions, with less capacity to adapt to new situations than you used to be?
never sometimes often always
24. How often are you more egotistic, paying less attention to other people's needs than you used to be?
never sometimes often always
25. How often are you more irritable than you used to be? How often do you easily lose your temper?
never sometimes often always
26. How often do you have crying episodes?
never sometimes often always
27. How often do you laugh at inappropriate situations?
never sometimes often always
28. How often are you more interested in sexual themes, talking, or reading about sex than you used to be?
never sometimes often always

29. How much of the time are you no longer interested in hobbies or activities you used to like?

never sometimes often always

30. How often do you feel more depressed than you used to?

never sometimes often always

End of AQ-D questions

Heart failure anosognosia questions

31. How often do you have shortness of breath?

never sometimes often always

32. How often do you have leg swelling?

never sometimes often always

Relative/Care-giver Form Study ID: _____ Date: _____

Relationship to patient: _____

These questions ask about behaviors and thinking problems that some people experience. For each question, circle how often you notice the behavior in your relative.

1. How often does the patient have problems remembering the date?
never sometimes often always
2. How often does the patient have problems orienting him/herself in new places?
never sometimes often always
3. How often does the patient have problems remembering telephone conversations?
never sometimes often always
4. How often does the patient have problems understanding conversations?
never sometimes often always
5. How often does the patient have problems signing his/her signature?
never sometimes often always
6. How often does the patient have problems understanding what he/she reads in the newspaper?
never sometimes often always
7. How often does the patient have problems keeping his/her personal belongings in order?
never sometimes often always
8. How often does the patient have problems remembering where he/she leaves things in his/her house?
never sometimes often always

9. How often does the patient have problems writing notes or letters?
never sometimes often always
10. How often does the patient have problems handling money?
never sometimes often always
11. How often does the patient have problems orienting his/herself in your neighborhood?
never sometimes often always
12. How often does the patient have problems remembering his/her appointments?
never sometimes often always
13. How often does the patient have problems doing his/her favorite hobbies?
never sometimes often always
14. How often does the patient have problems communicating with people?
never sometimes often always
15. How often does the patient have problems performing mental calculations?
never sometimes often always
16. How often does the patient have problems remembering things he/she have to buy when he/she goes shopping?
never sometimes often always
17. How often does the patient have problems controlling his/her sphincters? (i.e. movement of urine and stool)
never sometimes often always
18. How often does the patient have problems understanding the plot of a movie?
never sometimes often always

19. How often does the patient have problems orienting him/herself in his/her house?

never sometimes often always

20. How often does the patient have problems performing household activities (cooking, cleaning fixing things, etc?)

never sometimes often always

21. How often does the patient have problems feeding him/herself?

never sometimes often always

22. How often does the patient have problems keeping his/her checkbook, accounts, payments, etc?

never sometimes often always

23. How often is the patient more rigid in his/her decisions, with less capacity to adapt to new situations than he/she used to be?

never sometimes often always

24. How often is the patient more egotistic, paying less attention to other people's needs than he/she used to be?

never sometimes often always

25. How often is the patient more irritable than he/she used to be? How often does he/she easily lose his/her temper?

never sometimes often always

26. How often does the patient have crying episodes?

never sometimes often always

27. How often does the patient laugh at inappropriate situations?

never sometimes often always

28. How often is the patient more interested in sexual themes, talking, or reading about sex than he/she used to be?
- never sometimes often always*
29. How much of the time is the patient no longer interested in hobbies or activities he/she used to like?
- never sometimes often always*
30. How often does the patient feel more depressed than he/she used to?
- never sometimes often always*

End of AQ-D questions

Heart failure anosognosia questions

31. How often does the patient have shortness of breath?
- never sometimes often always*
32. How often does the patient have leg swelling?
- never sometimes often always*

APPENDIX F
LETTER OF COOPERATION FROM
MIDWEST HEART SPECIALISTS

March 1, 2010

Catherine M. Murks, RN, APN-NP
Nurse Practitioner, Cardiac Transplant
The University of Chicago Medical Center
Room A-621, MC 2016
5841 S. Maryland Avenue
Chicago, IL 60637

Dear Ms. Murks:

This is a letter of support for your intended research at Midwest Heart Foundation. I am aware that you are a doctoral candidate at the Loyola University Chicago, Graduate School (Niehoff School of Nursing), currently active in the process of completing data collection for your dissertation research.

I understand that you will be present at the Midwest Heart Specialist's clinic site (either in Naperville, Winfield or Downer's Grove) to collect data for your dissertation. You will be collaborating with Dr. Maria Rosa Costanzo and will have access to her patients with heart failure.

You have described that participants who are eligible will be asked to perform several cognitive tests, including the Repeatable Battery for the Assessment of Neuropsychological Status and the Controlled Oral Word Association. These tests will take about 35 minutes to complete and you are been trained in the administration of both of these tests by a neuropsychologist. You will also ask the participants to complete two tools, the Self-Care in Heart Failure Index and the Anosognosia Questionnaire for Dementia. The Anosognosia Questionnaire for Dementia has a parallel form that is filled out by a care giver. It will take the participant approximately 15 minutes to fill out these tools and the caregiver approximately 5 minutes to fill out the tool.

I understand that you have contacted Dr. Maria Rosa Costanzo about the possibility of performing this research at your site and she is agreeable. On behalf of Midwest Heart Foundation I am glad to facilitate access these patients and to medical records for the pursuit of your research.

The following items will need to be completed prior to initiation of research activity:

- Completion of the CITI Program OHRP training
- Receipt of an approved copy of the consent form
- Receipt of the most recent IRB approval letter.
- Receipt of an executed confidentiality agreement
- Receipt of IRB approved research protocol

Once these documents are received you may begin research activity. I look forward to working with you in the pursuit of your endeavor.

Sincerely,

Karen Larimer APN, NP-C, PhD (c)
Director of Research

Cc: Maria Rosa Costanzo, MD
Lea Elder, RN, MSN, MBA
Dawn Imburgia, RN, MBA

APPENDIX G
FINAL APPROVED CONSENT DOCUMENT

**CONSENT/AUTHORIZATION BY SUBJECT FOR PARTICIPATION IN A RESEARCH
PROTOCOL**

Protocol Number: 16233A

Name of Subject: _____

Medical History Number: _____

STUDY TITLE: ACTS- HF: Attention, CogniTion and Self-management in Heart Failure

Doctors Directing Research: Savitri E. Fedson, MD

Address: 5841 S. Maryland, MC 2016, Chicago, IL 60637
(773) 702- 9396

Telephone Number:

Catherine M. Murks, RN, APN
5841 S. Maryland, MC 2016, Chicago, IL 60637
(773) 702- 9396

You are being asked to participate in a research study. A member of the research team will explain what is involved in this study and how it will affect you. This consent form describes the study procedures, the risks and benefits of participation, as well as how your confidentiality will be maintained. Please take your time to ask questions and feel comfortable making a decision whether to participate or not. This process is called informed consent. If you decide to participate in this study, you will be asked to sign this form.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to determine if problems with thinking interfere with an individual's ability to manage their heart failure. This study will also attempt to determine if an individual who finds it difficult to manage his or her heart failure spends more time in the hospital and to determine if an individual who has difficulty with thinking spends more time in the hospital.

This research is also being done to satisfy requirements for a doctoral degree in nursing from Loyola University Chicago pursued by Catherine Murks, RN, APN.

HOW MANY PEOPLE WILL TAKE PART IN THE STUDY?

About 150 people and their caregivers will take part in this study at the University of Chicago and at other sites in the Chicago suburbs.

WHAT IS INVOLVED IN THE STUDY?

If you decide to participate in the study you will be asked to name a person (caregiver) to participate in the study who will be able to complete some questions as part of this study about how often this person believes you

APPROVED

Version 12, August 26, 2010, Page 1 of 6

Consent Form Approved by the IRB April 24, 2011 - June 28, 2011

experience specific things like remembering where you put something or understanding a movie.

If you decide to participate in this study, you will be asked to attend a study visit within 30 days of enrollment in the study. This visit may or may not be held on the same day as a physician visit. You will be asked to bring the person who can answer those questions with you. If he or she is unable to attend, these questions can be answered by telephone. This person will not be informed of any of the results of the study tests being performed on you. This visit will take place at your physician's clinic area or at an alternate agreed upon site.

During this visit, you will be asked to complete a few tests to determine how well you think. First of all, you will be asked how lonely you are. After that, you will be asked to complete a series of 12 short tests. These tests will be administered by a trained nurse and will require you to repeat words, remember a short story, copy a figure, match lines, name pictures, list words in a specific category, repeat numbers, code boxes, recall a list of words, and remember if certain words were on a list. Finally, you will be asked to list as many words that begin with a specific letter of the alphabet that you can in one minute. You will be asked to repeat this word list a total of three times. At the conclusion of this visit, you will be asked to sign a medical release in the event that the research team needs to obtain medical records from an hospital other than the University of Chicago. The entire visit will take about 35 minutes.

You will be given a packet of questionnaires to be filled out at your convenience and mailed back to the researcher in a self-addressed stamped envelope. For one of these questionnaires, you will be asked to complete a list of 32 questions about how often you experience certain things like forgetting where your checkbook is, understanding a movie, losing control of your urine or stool or having shortness of breath. The person you named to participate in the study will be asked this same list of 32 questions about you. If you do not return these questionnaires in 30 days, the nurse researcher will contact you up to three times to remind you to complete the forms.

Another questionnaire in the packet is a fifteen item questionnaire about managing your heart failure. This questionnaire will ask you how often you perform certain things, like eating a low salt diet or weighing yourself, and whether or not you have had shortness of breath or ankle swelling in the last three months. If you have had shortness of breath or ankle swelling in the last three months, you will be asked what you did and how comfortable you felt with your action.

Because the scores of these tests could reflect your ability to manage your heart failure, your physician will be notified if you score outside of the normal range for any of these tests.

After this visit is completed, you will be contacted in ninety days from study

APPROVED

Version 12, August 26, 2010, Page 2 of 6

Consent Form Approved by the IRB April 24, 2011 - June 28, 2011

enrollment to determine if you have been admitted to any hospital since you were discharged prior to the research testing.

During this study, Dr. Savitri Fedson and her research team will collect information about you for the purposes of this research. This information will include demographic information about you such as your name, your telephone number and the name of a relative or caregiver. You will be asked about your race, your years of education, how lonely you are, and if you have someone who can answer some questions about you and who that person is. Other information will be gathered from your medical record, including your medical and psychiatric history, the severity of your heart failure, your age, and gender, and if you have any history of substance abuse.

HOW LONG WILL I BE IN THE STUDY?

We think you will be in the study for approximately three months.

Dr. Fedson may decide to take you off of the study without your consent if:

- You are unable to meet the requirements of the study;
- Your medical condition changes;
- New information becomes available that indicates that participation in this study is not in your best interest; or
- If the study is stopped.

WHAT ARE THE RISKS OF THE STUDY?

If you decide to participate in this study, there is a slight risk that information about you may be disclosed to individuals other than research personnel. Please see the 'What About Confidentiality' section for a description of the measures taken to protect your confidentiality.—

You may suffer from anxiety, frustration and fatigue during the study testing. While it is likely that this will happen, it is not serious. You may refuse to answer any question that makes you uncomfortable answering.

ARE THERE ANY BENEFITS TO TAKING PART IN THE STUDY?

There is no direct medical benefit to you. We hope the information learned from this study will benefit other individuals with heart failure in the future or aid in our understanding of their ability to manage their illness.

WHAT OTHER OPTIONS ARE THERE?

Instead of being in this study, you may choose not to participate. The decision whether or not you wish to participate in this study will not affect your care at the University of Chicago Hospitals.

WHAT ARE THE COSTS?

APPROVED

Version 12, August 26, 2010, Page 3 of 6

Consent Form Approved by the IRB April 24, 2011 - June 28, 2011

There will be no cost to you or your insurance company resulting from participation in this research study. However, you or your insurance company will be responsible for costs related to your usual medical care. Usual medical care costs include any and all services that are considered medically necessary for your disease.

WILL I BE PAID FOR MY PARTICIPATION?

Study participants will receive a \$10.00 gift card upon completion of all the study tools. If it is necessary for you to pay to park in the parking facility for your visit, a parking voucher will be provided for you.

WHAT ABOUT CONFIDENTIALITY?

Study records that identify you will be kept confidential. Once you have agreed to participate in the study, all study records will be identified by study number only and will be kept in a locked file cabinet in the researcher's locked office. Copies of the informed consent will be kept in a separate area, also in a locked cabinet. All study documents will be kept for a period of at least six years. Electronic files such as data files will include study number only and will be kept in a password protected file on a password protected personal computer. Only the primary investigator and her research team will have access to the information on the study forms. The data collected in this study will be used for the purpose described in this form. By signing this form, you are allowing the research team access to your medical records, which include Protected Health Information. Protected Health Information (PHI) consists of any health information that is collected about you, which could include your medical history and new information collected as a result of this study. The research team includes the individuals listed on this consent form and other personnel involved in this study at the University of Chicago.

Your records may be reviewed by federal agencies whose responsibility is to protect human subjects in research including the Office of Human Research Protections (OHRP). In addition, representatives of the University of Chicago, including the Institutional Review Board, a committee that oversees the research at the University of Chicago, may also view the records of the research. If your research record is reviewed by any of these groups, they may also need to review your entire medical record.

If health information is shared outside the University of Chicago, the same laws that the University of Chicago must obey may not protect your health information.

APPROVED

Version 12, August 26, 2010, Page 4 of 6

Consent Form Approved by the IRB April 24, 2011 - June 28, 2011

During your participation in this study, you will have access to your medical record. Dr. Fedson is not required to release to you research information that is not part of your medical record.

This consent form will be kept by the research team for at least six years. The study results will be kept in your research record and be used by the research team indefinitely. At the time of study completion, either the research information not already in your medical record will be destroyed or information identifying you will be removed from study results. Any research information in your medical record will be kept indefinitely.

Data from this study may be used in medical publications or presentations. Your name and other identifying information will be removed before this data is used. If we wish to use identifying information in publications, we will ask for your approval at that time.

WHAT ARE MY RIGHTS AS A PARTICIPANT?

Taking part in this study is voluntary. If you choose not to participate in this study, your care at the University of Chicago/University of Chicago Hospitals will not be affected.

You may choose not to participate at any time during the study. Leaving the study will not affect your care at the University of Chicago/University of Chicago Hospitals.

If you choose to no longer be in the study and you do not want any of your future health information to be used, you must inform Dr. Fedson in writing at the address on the first page. Dr. Fedson may still use your information that was collected prior to your written notice.

We will tell you about significant new information that may affect your willingness to stay in this study.

You will be given a signed copy of this document. This consent form document does not have an expiration date.

WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?

You have talked to Dr. Savitri Fedson or Catherine Murks about this study and you had the opportunity to ask questions concerning any and all aspects of the research. If you have further questions about the study, you may call Catherine Murks at (773) 702-9396.

If you have any questions concerning your rights in this research study you may contact the Institutional Review Board, which is concerned with the protection of subjects in research projects. You may reach the Committee office between 8:30 am and 5:00 pm, Monday through Friday, by calling (773) 702-6505 or by writing:

APPROVED

Version 12, August 26, 2010, Page 5 of 6

Consent Form Approved by the IRB April 24, 2011 - June 28, 2011

CONSENT

SUBJECT

The research project and the procedures associated with it have been explained to me. The experimental procedures have been identified and no guarantee has been given about the possible results. I will receive a signed copy of this consent form for my records.

I agree to participate in this study. My participation is voluntary and I do not have to sign this form if I do not want to be part of this research study.

Signature of Subject: _____
Date: _____ Time: _____ AM/PM (Circle)

PERSON OBTAINING CONSENT

I have explained to _____ the nature and purpose of the study and the risks involved. I have answered and will answer all questions to the best of my ability. I will give a signed copy of the consent form to the subject and family.

Signature of Person Obtaining Consent: _____
Date: _____ Time: _____ AM/PM (Circle)

INVESTIGATOR/PHYSICIAN:

Signature of Investigator/Physician _____
Date: _____ Time: _____ AM/PM (Circle)

APPROVED

Version 12, August 26, 2010, Page 6 of 6
Consent Form Approved by the IRB April 24, 2011 - June 28, 2011

APPENDIX H
SCREENING/DEMOGRAPHIC SHEET

Screening/Demographic Form

Inclusion Criteria:

English speaking?	Yes	No	Age:_____
History of HF > 6 months Duration _____	Yes	No	Gender: Male Female
EF \leq 40%	Yes	No	Years of education:_____
Presence of significant other or caregiver	Yes	No	Race: Caucasian African American
Shortness of breath or leg swelling in last 90 days	Yes	No	Hispanic Other

Exclusion Criteria:

Age > 75	No	Yes	NYHA class I II III IV
Known cognitive imparment	No	Yes	Date of enrollment:_____
Known history of dementia	No	Yes	Physician:_____
Current drug treated depression	No	Yes	Days admitted in next 90 days: _____
Current drug or alcohol abuse	No	Yes	

Medications:_____

Reason for readmission: _____

Ask aloud at measurement visit:

On a scale from 1 to 10, with 1 being the least lonely and 10 being the most lonely, how lonely are you? _____

Other: _____

APPENDIX I
RELIABILITY STATISTICS OF STUDY VARIABLES

Normality Assessment and Reliability of Study Variables

Variable	Skewness	Kurtosis	Kolmogorov-Smirnov Z	p	alpha
Participant age	-.349	-.359	.596	.869	
Participant yrs education	-.180	-.103	1.106	.173	
Participant loneliness	.942	-.474	2.195	.000	
List learning	-.267	-.006	.808	.532	
Story memory	-.474	.652	.737	.649	
Figure copy	-.294	-.214	.835	.488	
Line orientation	-.465	.151	.890	.407	
Picture naming	-1.339	1.468	2.681	.000	
Semantic fluency	-.069	-.339	.843	.476	
Digit span	-.087	-.403	1.169	.130	
Coding	-.340	-.381	.960	.315	
List recall	.177	-.559	1.066	.206	
List recognition	-1.516	2.713	2.073	.000	
Story recall	-.433	-.344	.880	.421	
Figure recall	-.237	-.418	.981	.291	
Immediate memory	-.032	-.430	.943	.338	.679
Visuospatial index	.798	.516	1.281	.075	.415
Language index	-1.043	1.664	.875	.428	.243
Attention index	-.523	.473	.762	.606	.310
Delayed memory index	-1.339	1.689	1.363	.049	.651

Variable	Skewness	Kurtosis	Kolmogorov-Smirnov Z	p	alpha
RBANS total score	-.256	-.199	.938	.343	.791
COWAT	.705	.469	.812	.524	
AQ-D divergent	-.620	.777	1.120	.163	.841
SCHFI self maintenance	.106	-.846	1.083	.192	.477
SCHFI self management	-.586	.549	.615	.844	.627
SCHFI self confidence	-0.16	-.616	.860	.450	.774
HF anosognosia participant	.498	-.036	1.779	.004	
HF anosognosia caregiver	.853	.711	1.809	.003	
HF anosognosia divergent	.883	1.515	1.923	.001	

APPENDIX J

DESCRIPTIVE STATISTICS OF THE
REPEATABLE BATTERY FOR THE ASSESSMENT OF
NEUROPSYCHOLOGICAL STATUS

Descriptive Statistics for RBANS

<i>Test</i>	<i>Mean (S.D.)</i>	<i>Range</i>
List learning	24.25(4.87)	12-35
Story memory	15.4 (4.1)	2-23
Figure copy	12.61(3.78)	3-20
Line orientation	14.07(3.60)	3-20
Picture naming	9.38(.803)	7-10
Semantic fluency	18.5(4.40)	6-28
Digit span	10.2(2.51)	5-16
Coding	40.15(10.1)	15-61
List recall	4.94(1.96)	1-9
List recognition	18.98(1.16)	15-20
Story recall	7.91(2.36)	2-12
Figure recall	8.85(3.29)	2-16

APPENDIX K
DESCRIPTIVE STATISTICS OF THE
ANOSOGNOSIA QUESTIONNAIRE-
DEMENTIA

Descriptive statistics for AQ-D questions

<i>Question</i>	<i>Participant Mean (SD)</i>	<i>Range</i>	<i>Caregiver Mean (SD)</i>	<i>Range</i>	<i>Divergent Mean (SD)</i>	<i>Range</i>
Remembering date?	.93(.66)	0-3	.63(.64)	0-2	-.34(.73)	(-)3-1
Orienting in new places?	.77(.75)	0-3	.48(.67)	0-2	-.29(.83)	(-)2-2
Remembering conversations?	.829(.76)	0-3	.56(.71)	0-3	-.24(.91)	(-)3-2
Understanding conversations?	.73 (.64)	0-2	.37(.60)	0-2	-.30(.66)	(-)2-1
Signing signature?	.14(.46)	0-3	.11(.41)	0-2	-.02(.42)	(-)1-2
Understanding reading?	.46(.65)	0-2	.22(.49)	0-2	-.15(.56)	(-)1-1
Ordering personal items?	.74(.79)	0-3	.69(.91)	0-3	.03(.94)	(-)3-3
Remembering where things left?	1.13(.70)	0-3	1.07(.77)	0-3	.02(.83)	(-)3-2
Writing notes?	.50(.76)	0-3	.28(.65)	0-3	-.13(.75)	(-)2-2
Handling money?	.24(.58)	0-3	.25(.54)	0-2	.06(.56)	(-)1-2
Orienting in neighborhood?	.17(.38)	0-1	.11(.32)	0-1	-.03(.36)	(-)1-1
Remembering appointments?	.87(.70)	0-3	.64(.60)	0-2	-.10(.79)	(-)2-1
Favorite hobbies	.53(.78)	0-3	.27(.54)	0-2	-.24(.87)	(-)3-2
Communicating with people?	.53(.65)	0-3	.43(.62)	0-2	-.06(.74)	(-)2-2
Mental calculations?	.77(.68)	0-3	.44(.64)	0-2	-.29(.83)	(-)3-1
Remembering what to buy?	1.11(.73)	0-3	.84(.72)	0-3	-.27(.88)	(-)3-1
Controlling sphincters?	.40(.60)	0-3	.25(.53)	0-2	-.14(.64)	(-)3-1
Understanding plot of movie?	.59(.63)	0-3	.30(.53)	0-2	-.25(.59)	(-)1-1
Orienting self in home?	.23(.52)	0-3	.11(.36)	0-2	-.10(.39)	(-)1-1

<i>Question</i>	<i>Participant Mean (SD)</i>	<i>Range</i>	<i>Caregiver Mean (SD)</i>	<i>Range</i>	<i>Divergent Mean (SD)</i>	<i>Range</i>
Performing household activities?	.73(.87)	0-3	.57(.80)	0-3	-.18(.96)	(-)3-3
Feeding self?	.06(.23)	0-1	.02(.13)	0-1	-.03(.25)	(-)1-1
Keeping checkbook?	.35(.53)	0-2	.32(.64)	0-2	-.01(.67)	(-)2-2
Rigid in decisions?	.77(.73)	0-3	.69(.71)	0-3	-.07(.76)	(-)2-1
More egotistic?	.69(.65)	0-3	.55(.70)	0-3	-.14(.83)	(-)2-2
More irritable?	1.03(.82)	0-3	1.13(.79)	0-3	.18(.85)	(-)2-2
Crying?	.60(.71)	0-3	.41(.52)	0-2	-.13(.64)	(-)2-1
Laugh inappropriately?	.46(.61)	0-2	.18(.38)	0-1	-.26(.65)	(-)2-1
Sexual interest?	.41(.55)	0-2	.35(.65)	0-3	-.05(.75)	(-)2-3
Not interested in hobbies?	.86(.82)	0-3	.60(.71)	0-3	-.29(.89)	(-)2-3
More depressed?	.97(.78)	0-3	.97(.74)	0-3	.064(.84)	(-)2-2

APPENDIX L
CORRELATIONS BETWEEN
STUDY VARIABLES

Correlation matrix of study variables

<i>r</i> <i>sig</i> (2-tailed)	1	2	3	4	5	6	7	8	9
1. Participant age	1								
2. Male gender	.101 .405	1							
3. Years education	.149 .217	-.009 .939	1						
4. Minority race	-.334 .005	-.099 .413	-.008 .947	1					
5. Participant loneliness	-.201 .095	.071 .562	-.120 .324	.050 .683	1				
6. List learning	-.205 .089	-.206 .087	.262 ¹ .029	-.091 .453	.078 .522	1			
7. Story memory	.127 .294	.043 .725	.378 .001	-.205 .089	-.071 .560	.522 .000	1		
8. Figure copy	-.138 .256	.188 .119	.202 .093	-.143 .239	-.043 .721	.218 .070	.123 .311	1	
9. Line orientation	-.052 .669	.355 .003	.203 .092	-.233 .052	.051 .673	.182 .131	.295 .013	.262 .028	1
10. Picture naming	.218 .069	.120 .322	.314 .008	-.341 .004	-.171 .158	.189 .117	.410 .000	.054 .655	.135 .264
11. Semantic fluency	-.132 .275	-.072 .553	.508 .000	-.158 .190	-.020 .867	.492 .000	.421 .000	.314 .008	.207 .086
12. Digit span	-.147 .226	.211 .079	.186 .123	-.266 .026	-.154 .202	.247 .039	.319 .007	.294 .014	.184 .128
13. Coding	-.062 .609	.048 .691	.263 .028	-.410 .000	-.097 .423	.330 .005	.405 .001	.464 .000	.348 .003
14. List recall	-.180 .136	-.233 .052	.222 .065	-.174 .151	.037 .761	.681 .000	.569 .000	.141 .244	.136 .262
15. List recognition	-.005 .968	-.235 .050	.292 .014	-.086 .480	.016 .898	.490 .000	.430 .000	.042 .733	.042 .731
16. Story recall	.060 .622	-.009 .941	.398 .001	-.252 .035	-.087 .475	.421 .000	.821 .000	.269 .024	.374 .001
17. Figure recall	-.168 .164	.013 .918	.318 .007	-.205 .088	-.145 .230	.270 .024	.187 .121	.597 .000	.180 .136
18. RBANS Immediate memory	.121 .317	-.064 .600	.348 .003	-.181 .133	-.028 .815	.831 .000	.842 .000	.160 .185	.276 .021

<i>r</i> <i>sig</i> (2-tailed)	1	2	3	4	5	6	7	8	9
19.RBANS Visuospatial/ constuctional	.034 .781	.252 .035	.202 .094	-.254 .034	-.024 .846	.259 .031	.266 .026	.693 .000	.720 .000
20. RBANS Language	.148 .220	-.085 .484	.461 .000	-.258 .031	-.176 .146	.347 .003	.486 .000	.213 .077	.159 .188
21. RBANS Attention	.217 .071	.173 .152	.320 .007	-.477 .000	-.233 .052	.268 .025	.431 .000	.379 .001	.273 .022
22. RBANS Delayed mem.	.322 .007	-.172 .153	.450 .000	-.291 .014	-.138 .255	.397 .001	.577 .000	.186 .123	.135 .263
23. RBANS Total	.228 .057	.029 .814	.483 .000	-.409 .000	-.168 .163	.590 .000	.737 .000	.448 .000	.425 .000
24. COWAT	.215 .073	.032 .790	.354 .003	-.265 .027	-.210 .081	.305 .010	.456 .000	.304 .010	.158 .190
25. AQ-D patient	-.253 .034	-.117 .334	-.314 .008	.179 .139	.271 .023	-.011 .927	-.095 .436	-.207 .085	-.081 .506
26. AQ-D caregiver	-.047 .712	.059 .647	-.374 .003 ²	.001 .993	.132 .303	-.153 .230	-.148 .248	-.225 .076	-.020 .877
27. AQ-D divergent	.016 .903	.143 .265	-.038 .766	-.225 .076	-.046 .719	-.010 .936	-.017 .896	.027 .831	.083 .516
28. Self- maintenance	.340 ² .004	.118 .330	.180 .136	-.226 .060	.014 .908	-.046 .708	-.001 .996	-.017 .888	-.032 .792
29. Self- management	.062 .670	-.027 .854	.178 .215	.077 .595	-.038 .793	-.111 .441	-.042 .774	.005 .974	-.006 .967
30. Self- confidence	.196 .104	.003 .977	.029 .813	-.290 .015	-.354 .003	-.219 .069	-.228 .058	-.171 .157	-.030 .808
31. HF anosog-part	-.106 .382	-.252 .035	-.094 .441	.056 .643	.193 .109	.006 .964	.023 .851	-.198 .100	-.080 .508
32. HF anosog-CG	-.106 .408	-.175 .171	.010 .941	.152 .234	.185 .146	.118 .356	.142 .268	-.070 .586	-.097 .450
33. HF anosog-diverg	-.031 .813	.069 .600	.091 .486	.086 .509	.075 .567	.053 .684	.115 .379	.125 .338	-.042 .748

<i>r/sig 2-tailed</i>	<i>10</i>	<i>11</i>	<i>12</i>	<i>13</i>	<i>14</i>	<i>15</i>	<i>16</i>	<i>17</i>	<i>18</i>
10. Picture naming	1								
11. Semantic fluency	.391 .001	1							
12. Digit span	.319 .007	.337 .004	1						
13. Coding	.186 .124	.434 .000	.393 .001	1					
14. List recall	.189 .118	.414 .000	.211 .080	.315 .008	1				
15. List recognition	.332 .005	.282 .016	.140 .248	.215 .074	.553 .000	1			
16. Story recall	.428 .000	.409 .000	.256 ¹ .033	.456 .000	.522 .000	.368 .002	1		
17. Figure recall	.212 .078	.373 .001	.206 .087	.480 .000	.267 .025	.189 .118	.408 .000	1	
18. RBANS Immediate memory	.373 .001	.461 .000	.282 .018	.366 .002	.692 .000	.519 .000	.693 .000	.204 .090	1
19. RBANS Visuospatial/constuctional	.148 .222	.326 .006	.292 .014	.466 .000	.127 .295	.074 .540	.357 .002	.368 .002	.340 .004
20. RBANS Language	.666 .000	.851 .000	.301 .011	.365 .002	.308 .009	.289 .015	.440 .000	.295 .013	.472 .000
21. RBANS Attention	.386 .001	.409 .000	.757 .000	.782 .000	.224 .062	.227 .059	.397 .001	.305 .010	.416 .000
22. RBANS Delayed memory	.436 .000	.331 .005	.082 .501	.388 .001	.579 .000	.766 .000	.635 .000	.452 .000	.598 .000
23. RBANS Total	.531 .000	.641 .000	.503 .000	.669 .000	.544 .000	.518 .000	.705 .000	.442 .000	.793 .000
24. COWAT	.456 .000	.455 .000	.325 .006	.456 .000	.318 .007	.324 .006	.491 .000	.424 .000	.440 .000
25. AQ-D patient	-.275 .021	-.092 .447	.006 .959	-.199 .098	-.026 .834	-.174 .150	-.148 .220	-.408 .000	-.100 .409
26. AQ-D caregiver	-.091 .480	-.208 .102	-.093 .469	-.213 .094	-.301 .016	-.158 .216	-.130 .310	-.445 .000	-.153 .232
27. AQ-D divergent	.126 .326	-.015 .909	-.078 .543	.127 .322	-.147 .250	.033 .852	.024 .852	.028 .828	-.023 .855
28. Self-maintenance	-.053 .664	-.030 .804	-.136 .263	.074 .541	.027 .823	.077 .529	-.069 .573	-.003 .983	.001 .996
29. Self-management	-.041 .778	.068 .640	-.083 .568	-.033 .822	-.107 .459	-.093 .521	-.118 .413	-.163 .259	-.115 .428

<i>r/sig 2-tailed</i>	<i>10</i>	<i>11</i>	<i>12</i>	<i>13</i>	<i>14</i>	<i>15</i>	<i>16</i>	<i>17</i>	<i>18</i>
30. Self-confidence	.138 .253	.060 .621	-.002 .990	-.087 .474	-.238 .047	.138 .254	-.232 .053	.000 1.00	-.251 .036
31. HF anosog-part	-.115 .344	-.046 .706	.122 .314	-.042 .730	.043 .725	-.101 .404	-.005 .964	-.224 .063	-.013 .914
32. HF anosog-CG	-.135 .293	.153 .233	.076 .555	-.157 .219	-.053 .681	-.203 .110	.030 .816	-.149 .244	.101 .432
33. HF anosog-diverg	-.024 .854	.189 .146	-.072 .583	-.107 .413	-.127 .329	-.168 .196	-.003 .979	.085 .512	.060 .648

<i>r/sig 2-tailed</i>	<i>19</i>	<i>20</i>	<i>21</i>	<i>22</i>	<i>23</i>	<i>24</i>	<i>25</i>	<i>26</i>
19. RBANS Visuospatial/constuctional	1							
20. RBANS Language	.284 .017	1						
21. RBANS Attention	.452 .000	.436 .000	1					
22. RBANS Delayed memory	.200 .098	.412 .000	.385 .001	1				
23. RBANS Total	.622 .000	.688 ² .000	.770 .000	.717 .000	1			
24. COWAT	.319 .007	.506 .000	.514 .000	.483 .000	.629 .000	1		
25. AQ-D patient	-.153 .206	-.191 .114	-.226 .059	-.403 .001	-.293 .014	-.308 .009	1	
26. AQ-D caregiver	-.022 .861	-.151 .239	-.186 .144	-.430 .000 ²	-.265 .036	-.085 .506	.474 .000	1
27. AQ-D divergent	.101 .433	.057 .656	.048 .711	-.065 .613	.020 .875	.242 .056	-.530 .000	.488 .000
28. Self-maintenance	-.073 .548	-.008 .949	.024 .843	.141 .245	.016 .897	.004 .972	-.103 .396	-.171 .179
29. Self-management	-.083 .568	.001 .997	-.067 .645	-.149 .301	-.108 .453	-.085 .559	-.068 .637	-.135 .383
30. Self-confidence	-.108 .372	.129 .289	.022 .856	.054 .658	-.058 .634	.070 .567	-.129 .287	.077 .546
31. HF anosog-part	-.184 .128	-.103 .394	.019 .876	-.124 .306	-.092 .451	-.188 .120	.492 ² .000	.169 .186
32. HF anosog-CG	-.078 .546	.136 .289	-.095 .458	-.199 .118	-.036 .780	-.346 .005	.300 .017	.150 .239
33. HF anosog-divergent	.082 .531	.226 .079	-.143 .272	-.118 .364	.014 .916	-.111 .396	-.145 .266	-.018 .892

<i>r/sig 2-tailed</i>	<i>27</i>	<i>28</i>	<i>29</i>	<i>30</i>	<i>31</i>	<i>32</i>	<i>33</i>
27. AQ-D divergent	1						
28. Self- maintenance	-.018 .898	1					
29. Self- management	-.047 .764	.431 .002	1				
30. Self- confidence	.147 .250	.165 .172	.346 .014	1			
31. HF anosog- part	- .364 ² .003	-.112 .355	.222 .121	-.068 .578	1		
32. HF anosog- CG	-.155 .224	-.176 .167	.152 .325	-.051 .694	.469 .000	1	
33. HF anosog- diverg	.135 .301	-.101 .441	-.084 .597	-.025 .849	-.409 ² .001	.579 .000	1

APPENDIX M
PERMISSIONS

Printable License

Page 1 of 5

**ELSEVIER LICENSE
TERMS AND CONDITIONS**

Apr 28, 2011

This is a License Agreement between Catherine M Murks ("You") and Elsevier ("Elsevier") provided by Copyright Clearance Center ("CCC"). The license consists of your order details, the terms and conditions provided by Elsevier, and the payment terms and conditions.

All payments must be made in full to CCC. For payment instructions, please see information listed at the bottom of this form.

Supplier	Elsevier Limited The Boulevard, Langford Lane Kidlington, Oxford, OX5 1GB, UK
Registered Company Number	1982084
Customer name	Catherine M Murks
Customer address	1901 Tullip Lane Munster, IN 46321
License number	2657931106442
License date	Apr 28, 2011
Licensed content publisher	Elsevier
Licensed content publication	Journal of Cardiac Failure
Licensed content title	Psychometric testing of the self-care of heart failure index
Licensed content author	Barbara Riegel, Beverly Carlson, Debra K. Moser, Marge Sebern, Frank D. Hicks, Virginia Roland
Licensed content date	August 2004
Licensed content volume number	10
Licensed content issue number	4
Number of pages	11
Start Page	350
End Page	360
Type of Use	reuse in a thesis/dissertation
Portion	figures/tables/illustrations
Number of figures/tables/illustrations	6
Format	both print and electronic
Are you the author of this Elsevier article?	No
Will you be translating?	No

<https://s100.copyright.com/App/PrintableLicenseFrame.jsp?publisherID=70&licenseID=2...> 4/28/2011

Order reference number	
Title of your thesis/dissertation	ACTS-HF: Attention, Cognition and Self-Care in Heart Failure
Expected completion date	Aug 2011
Estimated size (number of pages)	310
Elsevier VAT number	GB 494 6272 12
Permissions price	0.00 USD
VAT/Local Sales Tax	0.0 USD / 0.0 GBP
Total	0.00 USD
Terms and Conditions	

INTRODUCTION

1. The publisher for this copyrighted material is Elsevier. By clicking "accept" in connection with completing this licensing transaction, you agree that the following terms and conditions apply to this transaction (along with the Billing and Payment terms and conditions established by Copyright Clearance Center, Inc. ("CCC"), at the time that you opened your Rightslink account and that are available at any time at <http://myaccount.copyright.com>).

GENERAL TERMS

2. Elsevier hereby grants you permission to reproduce the aforementioned material subject to the terms and conditions indicated.
3. Acknowledgement: If any part of the material to be used (for example, figures) has appeared in our publication with credit or acknowledgement to another source, permission must also be sought from that source. If such permission is not obtained then that material may not be included in your publication/copies. Suitable acknowledgement to the source must be made, either as a footnote or in a reference list at the end of your publication, as follows:
 "Reprinted from Publication title, Vol /edition number, Author(s), Title of article / title of chapter, Pages No., Copyright (Year), with permission from Elsevier (OR APPLICABLE SOCIETY COPYRIGHT OWNER)." Also Lancet special credit - "Reprinted from The Lancet, Vol. number, Author(s), Title of article, Pages No., Copyright (Year), with permission from Elsevier."
4. Reproduction of this material is confined to the purpose and/or media for which permission is hereby given.
5. Altering/Modifying Material: Not Permitted. However figures and illustrations may be altered/adapted minimally to serve your work. Any other abbreviations, additions, deletions and/or any other alterations shall be made only with prior written authorization of Elsevier Ltd. (Please contact Elsevier at permissions@elsevier.com)
6. If the permission fee for the requested use of our material is waived in this instance,

please be advised that your future requests for Elsevier materials may attract a fee.

7. Reservation of Rights: Publisher reserves all rights not specifically granted in the combination of (i) the license details provided by you and accepted in the course of this licensing transaction, (ii) these terms and conditions and (iii) CCC's Billing and Payment terms and conditions.

8. License Contingent Upon Payment: While you may exercise the rights licensed immediately upon issuance of the license at the end of the licensing process for the transaction, provided that you have disclosed complete and accurate details of your proposed use, no license is finally effective unless and until full payment is received from you (either by publisher or by CCC) as provided in CCC's Billing and Payment terms and conditions. If full payment is not received on a timely basis, then any license preliminarily granted shall be deemed automatically revoked and shall be void as if never granted. Further, in the event that you breach any of these terms and conditions or any of CCC's Billing and Payment terms and conditions, the license is automatically revoked and shall be void as if never granted. Use of materials as described in a revoked license, as well as any use of the materials beyond the scope of an unrevoked license, may constitute copyright infringement and publisher reserves the right to take any and all action to protect its copyright in the materials.

9. Warranties: Publisher makes no representations or warranties with respect to the licensed material.

10. Indemnity: You hereby indemnify and agree to hold harmless publisher and CCC, and their respective officers, directors, employees and agents, from and against any and all claims arising out of your use of the licensed material other than as specifically authorized pursuant to this license.

11. No Transfer of License: This license is personal to you and may not be sublicensed, assigned, or transferred by you to any other person without publisher's written permission.

12. No Amendment Except in Writing: This license may not be amended except in a writing signed by both parties (or, in the case of publisher, by CCC on publisher's behalf).

13. Objection to Contrary Terms: Publisher hereby objects to any terms contained in any purchase order, acknowledgment, check endorsement or other writing prepared by you, which terms are inconsistent with these terms and conditions or CCC's Billing and Payment terms and conditions. These terms and conditions, together with CCC's Billing and Payment terms and conditions (which are incorporated herein), comprise the entire agreement between you and publisher (and CCC) concerning this licensing transaction. In the event of any conflict between your obligations established by these terms and conditions and those established by CCC's Billing and Payment terms and conditions, these terms and conditions shall control.

14. Revocation: Elsevier or Copyright Clearance Center may deny the permissions described in this License at their sole discretion, for any reason or no reason, with a full refund payable to you. Notice of such denial will be made using the contact information provided by you. Failure to receive such notice will not alter or invalidate the denial. In no event will Elsevier or Copyright Clearance Center be responsible or liable for any costs, expenses or damages.

incurred by you as a result of a denial of your permission request, other than a refund of the amount(s) paid by you to Elsevier and/or Copyright Clearance Center for denied permissions.

LIMITED LICENSE

The following terms and conditions apply only to specific license types:

15. **Translation:** This permission is granted for non-exclusive world ~~English~~ rights only unless your license was granted for translation rights. If you licensed translation rights you may only translate this content into the languages you requested. A professional translator must perform all translations and reproduce the content word for word preserving the integrity of the article. If this license is to re-use 1 or 2 figures then permission is granted for non-exclusive world rights in all languages.

16. **Website:** The following terms and conditions apply to electronic reserve and author websites:

Electronic reserve: If licensed material is to be posted to website, the web site is to be password-protected and made available only to bona fide students registered on a relevant course if:

This license was made in connection with a course.

This permission is granted for 1 year only. You may obtain a license for future website posting.

All content posted to the web site must maintain the copyright information line on the bottom of each image.

A hyper-text must be included to the Homepage of the journal from which you are licensing at <http://www.sciencedirect.com/science/journal/xxxxx> or the Elsevier homepage for books at <http://www.elsevier.com>, and

Central Storage: This license does not include permission for a scanned version of the material to be stored in a central repository such as that provided by Heron/XanEdu.

17. **Author website** for journals with the following additional clauses:

All content posted to the web site must maintain the copyright information line on the bottom of each image, and

the permission granted is limited to the personal version of your paper. You are not allowed to download and post the published electronic version of your article (whether PDF or HTML, proof or final version), nor may you scan the printed edition to create an electronic version.

A hyper-text must be included to the Homepage of the journal from which you are licensing at <http://www.sciencedirect.com/science/journal/xxxxx>. As part of our normal production process, you will receive an e-mail notice when your article appears on Elsevier's online service ScienceDirect (www.sciencedirect.com). That e-mail will include the article's Digital Object Identifier (DOI). This number provides the electronic link to the published article and should be included in the posting of your personal version. We ask that you wait until you receive this e-mail and have the DOI to do any posting.

Central Storage: This license does not include permission for a scanned version of the material to be stored in a central repository such as that provided by Heron/XanEdu.

18. **Author website** for books with the following additional clauses:

Authors are permitted to place a brief summary of their work online only.
A hyper-text must be included to the Elsevier homepage at <http://www.elsevier.com>

All content posted to the web site must maintain the copyright information line on the bottom of each image

You are not allowed to download and post the published electronic version of your chapter, nor may you scan the printed edition to create an electronic version.

Central Storage: This license does not include permission for a scanned version of the material to be stored in a central repository such as that provided by Heron/XanEdu.

19. Website (regular and for author): A hyper-text must be included to the Homepage of the journal from which you are licensing at <http://www.sciencedirect.com/science/journal/xxxxx>, or for books to the Elsevier homepage at <http://www.elsevier.com>

20. Thesis/Dissertation: If your license is for use in a thesis/dissertation your thesis may be submitted to your institution in either print or electronic form. Should your thesis be published commercially, please reapply for permission. These requirements include permission for the Library and Archives of Canada to supply single copies, on demand, of the complete thesis and include permission for UMI to supply single copies, on demand, of the complete thesis. Should your thesis be published commercially, please reapply for permission.

21. Other Conditions:

v1.6

Gratis licenses (referencing \$0 in the Total field) are free. Please retain this printable license for your reference. No payment is required.

If you would like to pay for this license now, please remit this license along with your payment made payable to "COPYRIGHT CLEARANCE CENTER" otherwise you will be invoiced within 48 hours of the license date. Payment should be in the form of a check or money order referencing your account number and this invoice number RLNK10078846.

Once you receive your invoice for this order, you may pay your invoice by credit card. Please follow instructions provided at that time.

Make Payment To:
Copyright Clearance Center
Dept 001
P.O. Box 843006
Boston, MA 02284-3006

For suggestions or comments regarding this order, contact Rightslink Customer Support: customer@copyright.com or +1-877-622-5843 (toll free in the US) or +1-978-646-2777.

**ELSEVIER LICENSE
TERMS AND CONDITIONS**

Apr 28, 2011

This is a License Agreement between Catherine M Murks ("You") and Elsevier ("Elsevier") provided by Copyright Clearance Center ("CCC"). The license consists of your order details, the terms and conditions provided by Elsevier, and the payment terms and conditions.

All payments must be made in full to CCC. For payment instructions, please see information listed at the bottom of this form.

Supplier	Elsevier Limited The Boulevard, Langford Lane Kidlington, Oxford, OX5 1GB, UK
Registered Company Number	1982084
Customer name	Catherine M Murks
Customer address	1901 Tullip Lane Munster, IN 46321
License number	2657941032457
License date	Apr 28, 2011
Licensed content publisher	Elsevier
Licensed content publication	Neuropsychologia
Licensed content title	The left frontal lobe of man and the suppression of habitual responses in verbal categorical behaviour
Licensed content author	E. Perret
Licensed content date	July 1974
Licensed content volume number	12
Licensed content issue number	3
Number of pages	8
Start Page	323
End Page	330
Type of Use	reuse in a thesis/dissertation
Intended publisher of new work	other
Portion	figures/tables/illustrations
Number of figures/tables/illustrations	1
Format	both print and electronic
Are you the author of this Elsevier article?	No

<https://s100.copyright.com/App/PrintableLicenseFrame.jsp?publisherID=70&licenseID=2...> 4/28/2011

Rightslink Printable License

Page 2 of 6

Will you be translating? No

Order reference number

Title of your thesis/dissertation ACTS-HF: Attention, Cognition and Self-Care in Heart Failure

Expected completion date Aug 2011

Estimated size (number of pages) 310

Elsevier VAT number GB 494 6272 12

Permissions price 0.00 USD

VAT/Local Sales Tax 0.0 USD / 0.0 GBP

Total 0.00 USD

Terms and Conditions

INTRODUCTION

1. The publisher for this copyrighted material is Elsevier. By clicking "accept" in connection with completing this licensing transaction, you agree that the following terms and conditions apply to this transaction (along with the Billing and Payment terms and conditions established by Copyright Clearance Center, Inc. ("CCC"), at the time that you opened your Rightslink account and that are available at any time at <http://myaccount.copyright.com>).

GENERAL TERMS

2. Elsevier hereby grants you permission to reproduce the aforementioned material subject to the terms and conditions indicated.
3. Acknowledgement: If any part of the material to be used (for example, figures) has appeared in our publication with credit or acknowledgement to another source, permission must also be sought from that source. If such permission is not obtained then that material may not be included in your publication/copies. Suitable acknowledgement to the source must be made, either as a footnote or in a reference list at the end of your publication, as follows:
- "Reprinted from Publication title, Vol /edition number, Author(s), Title of article / title of chapter, Pages No., Copyright (Year), with permission from Elsevier [OR APPLICABLE SOCIETY COPYRIGHT OWNER]." Also Lancet special credit - "Reprinted from The Lancet, Vol. number, Author(s), Title of article, Pages No., Copyright (Year), with permission from Elsevier."
4. Reproduction of this material is confined to the purpose and/or media for which permission is hereby given.
5. Altering/Modifying Material: Not Permitted. However figures and illustrations may be altered/adapted minimally to serve your work. Any other abbreviations, additions, deletions and/or any other alterations shall be made only with prior written authorization of Elsevier Ltd. (Please contact Elsevier at permissions@elsevier.com)

please be advised that your future requests for Elsevier materials may attract a fee.

7. Reservation of Rights: Publisher reserves all rights not specifically granted in the combination of (i) the license details provided by you and accepted in the course of this licensing transaction, (ii) these terms and conditions and (iii) CCC's Billing and Payment terms and conditions.

8. License Contingent Upon Payment: While you may exercise the rights licensed immediately upon issuance of the license at the end of the licensing process for the transaction, provided that you have disclosed complete and accurate details of your proposed use, no license is finally effective unless and until full payment is received from you (either by publisher or by CCC) as provided in CCC's Billing and Payment terms and conditions. If full payment is not received on a timely basis, then any license preliminarily granted shall be deemed automatically revoked and shall be void as if never granted. Further, in the event that you breach any of these terms and conditions or any of CCC's Billing and Payment terms and conditions, the license is automatically revoked and shall be void as if never granted. Use of materials as described in a revoked license, as well as any use of the materials beyond the scope of an unrevoked license, may constitute copyright infringement and publisher reserves the right to take any and all action to protect its copyright in the materials.

9. Warranties: Publisher makes no representations or warranties with respect to the licensed material.

10. Indemnity: You hereby indemnify and agree to hold harmless publisher and CCC, and their respective officers, directors, employees and agents, from and against any and all claims arising out of your use of the licensed material other than as specifically authorized pursuant to this license.

11. No Transfer of License: This license is personal to you and may not be sublicensed, assigned, or transferred by you to any other person without publisher's written permission.

12. No Amendment Except in Writing: This license may not be amended except in a writing signed by both parties (or, in the case of publisher, by CCC on publisher's behalf).

13. Objection to Contrary Terms: Publisher hereby objects to any terms contained in any purchase order, acknowledgment, check endorsement or other writing prepared by you, which terms are inconsistent with these terms and conditions or CCC's Billing and Payment terms and conditions. These terms and conditions, together with CCC's Billing and Payment terms and conditions (which are incorporated herein), comprise the entire agreement between you and publisher (and CCC) concerning this licensing transaction. In the event of any conflict between your obligations established by these terms and conditions and those established by CCC's Billing and Payment terms and conditions, these terms and conditions shall control.

14. Revocation: Elsevier or Copyright Clearance Center may deny the permissions described in this License at their sole discretion, for any reason or no reason, with a full refund payable to you. Notice of such denial will be made using the contact information provided by you. Failure to receive such notice will not alter or invalidate the denial. In no event will Elsevier or Copyright Clearance Center be responsible or liable for any costs, expenses or damage

incurred by you as a result of a denial of your permission request, other than a refund of the amount(s) paid by you to Elsevier and/or Copyright Clearance Center for denied permissions.

LIMITED LICENSE

The following terms and conditions apply only to specific license types:

15. Translation: This permission is granted for non-exclusive world ~~English~~ rights only unless your license was granted for translation rights. If you licensed translation rights you may only translate this content into the languages you requested. A professional translator must perform all translations and reproduce the content word for word preserving the integrity of the article. If this license is to re-use 1 or 2 figures then permission is granted for non-exclusive world rights in all languages.

16. Website: The following terms and conditions apply to electronic reserve and author websites:

Electronic reserve: If licensed material is to be posted to website, the web site is to be password-protected and made available only to bona fide students registered on a relevant course if:

This license was made in connection with a course,

This permission is granted for 1 year only. You may obtain a license for future website posting.

All content posted to the web site must maintain the copyright information line on the bottom of each image.

A hyper-text must be included to the Homepage of the journal from which you are licensing at <http://www.sciencedirect.com/science/journal/xxxxx> or the Elsevier homepage for books at <http://www.elsevier.com>, and

Central Storage: This license does not include permission for a scanned version of the material to be stored in a central repository such as that provided by Heron/XanEdu.

17. Author website for journals with the following additional clauses:

All content posted to the web site must maintain the copyright information line on the bottom of each image, and

the permission granted is limited to the personal version of your paper. You are not allowed to download and post the published electronic version of your article (whether PDF or HTML, proof or final version), nor may you scan the printed edition to create an electronic version.

A hyper-text must be included to the Homepage of the journal from which you are licensing at <http://www.sciencedirect.com/science/journal/xxxxx>. As part of our normal production process, you will receive an e-mail notice when your article appears on Elsevier's online service ScienceDirect (www.sciencedirect.com). That e-mail will include the article's Digital Object Identifier (DOI). This number provides the electronic link to the published article and should be included in the posting of your personal version. We ask that you wait until you receive this e-mail and have the DOI to do any posting.

Central Storage: This license does not include permission for a scanned version of the material to be stored in a central repository such as that provided by Heron/XanEdu.

18. Author website for books with the following additional clauses:

Authors are permitted to place a brief summary of their work online only.
A hyper-text must be included to the Elsevier homepage at <http://www.elsevier.com>

All content posted to the web site must maintain the copyright information line on the bottom of each image

You are not allowed to download and post the published electronic version of your chapter, nor may you scan the printed edition to create an electronic version.

Central Storage: This license does not include permission for a scanned version of the material to be stored in a central repository such as that provided by Heron/XanEdu.

19. Website (regular and for author): A hyper-text must be included to the Homepage of the journal from which you are licensing at <http://www.sciencedirect.com/science/journal/xxxxx> or for books to the Elsevier homepage at <http://www.elsevier.com>

20. Thesis/Dissertation: If your license is for use in a thesis/dissertation your thesis may be submitted to your institution in either print or electronic form. Should your thesis be published commercially, please reapply for permission. These requirements include permission for the Library and Archives of Canada to supply single copies, on demand, of the complete thesis and include permission for UMI to supply single copies, on demand, of the complete thesis. Should your thesis be published commercially, please reapply for permission.

21. Other Conditions:

v1.6

Gratis licenses (referencing 00 in the Total field) are free. Please retain this printable license for your reference. No payment is required.

If you would like to pay for this license now, please remit this license along with your payment made payable to "COPYRIGHT CLEARANCE CENTER" otherwise you will be invoiced within 48 hours of the license date. Payment should be in the form of a check or money order referencing your account number and this invoice number RLNN16678846.

Once you receive your invoice for this order, you may pay your invoice by credit card. Please follow instructions provided at that time.

Make Payment To:
Copyright Clearance Center
Dept 983
P.O. Box 843996
Boston, MA 02284-3996

For suggestions or comments regarding this order, contact Rightslink Customer Support: customercare@copyright.com or +1-877-622-5843 (toll free in the US) or +1-978-646-2777.

	LICENSE YOUR CONTENT PRODUCTS AND SOLUTIONS PARTNERS EDUCATION ABOUT US			
Back to view orders				
Copy order		Cancel Open Items		Add another item to this order
				Print this page Print terms & conditions Print citation information (What's this?)
Confirmation Number: 10338200 Order Date: 04/10/2011				
Customer Information				
Customer: Catherine Murks Account Number: 3000171820 Organization: Catherine Murks Email: cmurks@comcast.net Phone: +1 (219)9236050 Payment Method: Invoice				
Search order details by: <input type="text"/> Permission Status <input type="text"/> Granted <input type="button" value="Go"/>				
Order Details				
The Journal of neuropsychiatry and clinical neurosciences				
<div style="float: right; border: 1px solid black; padding: 2px;"> Billing Status: Not Billed </div>				
Order detail ID: 53416717		Permission Status: <input checked="" type="radio"/> Granted Comment: Thesis or Dissertation use only. Print and website only. No commercial use granted.		
ISSN: 0895-0172		Permission type: Republish or display content		
Publication year: 1995		Type of use: Dissertation		
Publication Type: Journal		Requested use: Dissertation		
Publisher: AMERICAN PSYCHIATRIC PUBLISHING, INC.		Republishing title: ACTS-HF: Attention, Cognition and Self-care in Heart Failure		
Author/Editor: Migliorelli, et al		Republishing organization: UMI/Proquest		
Your reference: Cathy's Dissertation		Organization status: For-profit		
		Republishing date: 08/01/2011		
		Circulation / Distribution: 1000		
		Type of content: Figure/ diagram/ table		
		Description of requested content: Table 1, Anosognosia Questionnaire- Dementia		
		Page range(s): 340		
		Translating to: No Translation		
		Requested content's publication date: 06/01/1995		
Cancel Copy Edit		\$ 3.50		
Total order items: 1		Order Total: \$3.50		

REFERENCE LIST

- Adams, K.F., Lindenfeld, J., Arnold, J.M.O., Baker, D.W., Barnard, D.H., Baughman, K.L., . . . Wagoner, L. (2006). HFSA comprehensive heart failure practice guideline. *Journal of Cardiac Failure*, 12, e1-e122.
- Akomolafe, A., Quarshie, A., Jackson, P., Thomas, J., Deffer, O., Oduwole, A., . . . Mayberry, R. (2005). The prevalence of cognitive impairment among African American patients with congestive heart failure. *Journal of the American Medical Association*, 297(5), 689-694.
- Aldred, H., Gott, M. & Gariballa, S. (2003). Advanced heart failure: Impact on older patients and informal carers. *Journal of Advanced Nursing*, 49(2), 116-24.
- Almeida, O.P. & Flicker, L. (2001). The mind of a failing heart: A systematic review of the association between HF and cognitive functioning. *Internal Medicine Journal*, 31, 290-95.
- Almeida, O.P. & Tamai, S. (2001). Congestive heart failure and cognitive functioning amongst older adults. *Arq Neuropsiquiatr*, 59(2-B), 324-329.
- Alzheimer's Association. (2004). Research consent for cognitively impaired adults: Recommendations for institutional review boards and investigators. *Alzheimer's Disease and Associated Disorders*, 18(3), 171-75.
- Arbuthnott, K. & Frank, J. (2000). Trail Making Test, Part B as a measure of executive control: Validation using a set-switching paradigm. *Journal of Clinical and Experimental Neuropsychology*, 22(4), 518-28.
- Artinian, N.T., Magnan, M. Sloan, M. & Lange, M.P. (2002). Self-care behaviors among patients with heart failure. *Heart & Lung*, 31(3), 161-172.
- Barr, W.B. (2003). Neuropsychological testing of high school athletes: Preliminary norms and test-retest indices. *Archives of Clinical Neuropsychology*, 18, 91-101.

- Basso, M.R., Bornstein, R.A. & Lang, J.M. (1999). Practice effects on commonly used measures of executive function across twelve months. *The Clinical Neuropsychologist*, 13(3), 283-92.
- Beatty, W.W. (2004). RBANS analysis of verbal memory in multiple sclerosis. *Archives of Clinical Neuropsychology*, 19, 825-34.
- Beatty, W.W. , Mold, J.W. & Gontkovsky, S.T. (2003). RBANS performance: Influence of sex and education. *Journal of Clinical and Experimental Neuropsychology*, 25(8), 1065-69.
- Beatty, W.W., Ryder, K.A., Gontkovsky, S.T., Scott, J.G., McSwan, K.L. & Bharucha, K.J. (2002). Analyzing the subcortical dementia syndrome of Parkinson's Disease using the RBANS. *Archives of Clinical Neuropsychology*, 18, 509-20.
- Beer, C., Ebenezer, E., FEnner, S., Lautenschlager, N.T., Arnolda, L., Flicker, L. & Almeeida. (2009). Contributors to cognitive impairment in congestive heart failure: A pilot case-control study. *Internal Medicine Journal*, 39, 600-605.
- Bell-McGinty, S., Podell, K., Franzen, M., Baird, A.D. & Williams, M.J. (2002). Standard measures of executive function in predicting instrumental activities of daily living in older adults. *International Journal of Geriatric Psychiatry*, 17, 828-34.
- Bennett, S., Baker, S.L., & Huster, G.A. (1998). Quality of life in women with heart failure. *Health Care for Women International*, 19, 217-29.
- Bennett, S.J., Cordes, D.K., Westmoreland, G., Castro, R. & Donnelly, E. (2000). Self-care strategies for symptom management in patients with chronic heart failure. *Nursing Research*, 49(3), 139-45.
- Bennett, S.J., Pressler, M.L., Hays, L., Firestine, L.A. & Huster, G.A. (1997). Psychosocial variables and hospitalizations in persons with chronic heart failure. *Progress in Cardiovascular Nursing*, 12(4), 4-11.
- Bennett, S.J. & Sauve, M.J. (2003). Cognitive deficits in patients with heart failure: A review of the literature. *Journal of Cardiovascular Nursing*, 18(3), 219-42.
- Benton, A.L. (1968). Differential behavioral effects in frontal lobe disease. *Neuropsychologia*, 6, 53-60.

- Blustein, J., Valentine, M., Mead, H., & Regenstein, M. (2008). Race/ethnicity and patient confidence to self-manage cardiovascular disease. *Medical Care*, 46(9), 924-929.
- Boeve, B., McCormick, J., Smith, G., Ferman, T., Rummans, T. Carpenter, T, . . . Peterson, R. (2003). Mild cognitive impairment in the oldest old. *Neurology*, 60(3), 477-480.
- Bornstein, R.A., Starling, R.C., Myerowitz., P., & Haas, G.J. (1995). Neuropsychological function in patients with end-stage heart failure before and after cardiac transplantation. *Acta Neurologica Scandinavica*, 91, 260-65.
- Brannstrom, M., Ekman, I., Norberg, A., Boman, K. & Strandberg, G. (2006). Living with severe chronic heart failure in palliative advanced home care. *European Journal of Cardiovascular Nursing*, 5, 295-302.
- Bristow, M.R., Saxon, L.A., Boehmer, J., Krueger, S., Kass, D.A., De Marco, T., . . . Feldman, A.M. (2004). Cardiac-resynchronization therapy with or without an implantable defibrillator in advanced chronic heart failure. *New England Journal of Medicine*, 350, 2140-50.
- Brooks, J., Fos, LA., Greve, K.W. & Hammond, J.S. (1999). Assessment of executive function in patients with mild traumatic brain injury. *The Journal of Trauma, Injury, Infection and Critical Care*, 46(1), 159-63.
- Bryan, J. & Luszcz, M.A. (2000). Measurement of executive function: Considerations for detecting adult age differences. *Journal of Clinical and Experimental Neuropsychology*, 22(1), 40-55.
- Cacciatore, F., Abete, P., Ferrra, N., Calabrese, C., Napoli, C., Maggi, S., Varricchio, M., & Rengo, F. (1998). Congestive heart failure and cognitive impairment in an older population. *Journal of the American Geriatrics Society*, 46, 1343-48.
- Callegari, S., Majani, G., Giardini, A., Dieroban, A., Opasich, C., Cobelli, F., . . . Tavazzi, L. (2002). Relationship between cognitive impairment and clinical status in chronic heart failure patients. *Monaldi Archives for Chest Diseases*, 58(1), 19-25.
- Cameron, J., Worrall-Carter, L., Riegel, B., Lo, S., & Stewart, S. (2009). Testing a model of patient characteristics, psychological status, and cognitive function as predictors of self-care in persons with chronic heart failure. *Heart and Lung*, 38(5), 410-418

- Cameron, J., Worrall-Carter, L., Page, K., Riegel, B., Lo, S. & Stewart, S. (2010). Does cognitive impairment predict poor self-care in patients with heart failure? *European Journal of Heart Failure*, 12, 508-15.
- Carlson, B., Riegel, B. & Moser, D.K. (2001). Self-care abilities of patients with heart failure. *Heart & Lung*, 30(5), 351-59.
- Chaytor, N., Schmitter-Edgecombe, M. & Burr, R. (2006). Improving the ecological validity of executive functioning assessment. *Archives of Clinical Neuropsychology*, 21, 217-27.
- Chemerinski, E., Petracca, G., Teson, A., Sabe, L., Leiguarda, R. & Starkstein, S. (1998). Prevalence and correlates of aggressive behavior in Alzheimer's disease. *Journal of Neuropsychiatry*, 10, 421-25.
- Chin, M. & Goldman, L. (1997). Correlates of early hospital readmission or death in patients congestive heart failure. *American Journal of Cardiology*, 79, 1640-44.
- CIBIS Investigators and Committees (1994). A randomized trial of beta-blockade in heart failure: The cardiac insufficiency bisoprolol study (CIBIS). *Circulation*, 90, 1765-73.
- CIBIS II Investigators and Committees (1999). The cardiac insufficiency bisoprolol study II (CIBIS II): A randomized trial. *Lancet*, 353, 9-13.
- Cleland, J.G. F., Daubert, J.C., Erdmann, E., Freemantle, N., Gras, D., Kappenberger, L. (2005). The effect of cardiac resynchronization on morbidity and mortality in heart failure. *New England Journal of Medicine*, 352, 1539-49.
- Cohn, J.N., Archibald, D.G., Ziesche, S., Franciosa, J.A., Harston, W.E., Tristani, F.E., . . . Baker, B. (1986). Effect of vasodilator therapy on mortality in chronic congestive heart failure: Results of a Veteran's Administration Cooperative study. *New England Journal of Medicine*, 314, 1547-1552.
- Cohn, J.N., Johnson, G., Ziesche, S., Cobb, F., Francis, G., Tristani, F., . . . Wong, M. (1991). A comparison of enalapril with hydralazine-isosorbide dinitrate in the treatment of chronic congestive heart failure. *New England Journal of Medicine*, 325, 303-10.
- Crean, R.D. (2003). Ecological validity of neuropsychological performance as a predictor of work outcome following mild traumatic brain injury. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 64(2-B), 958. (UMI No. 3080411).

- Dennison, C., McEntee, M.L., Samuel, L., Johnson, B.J., Rotman, S., Kielty, A. & Russell, S.D. (2010). Adequate health literacy is associated with higher heart failure knowledge and self-care confidence in hospitalized patients. *Journal of Cardiovascular Nursing*, Advance online publication. Doi: 10.1097/JCN.0B013E3181F16F88.
- Deshields, T.L., McDonough, E.M., Mannen, R.K., & Miller, L.W. (1996). Psychological and cognitive status before and after heart transplantation. *General Hospital Psychiatry*, 18, 62S-69S.
- Dickson, V., McCauley, L. & Riegel, B. (2008). Work-heart balance: The influences of biobehaviorable variables on self-care among employees. *AAOHN Journal*, 56(2), 63-73.
- Dickson, V.V., Riegel, B. & Tkacs, N. (2007). Cognitive influences on self-care decision making in persons with heart failure. *American Heart Journal*, 154(3), 424-31.
- Dixit, N., Vazquez, L., Cross, N., Kuhl, E., Serber, E., Kovacs, A. . . . Sears, S. (2010). Cardiac resynchronization therapy: A pilot study examining cognitive change in patients before and after treatment. *Clinical Cardiology*, 33(2), 84-88.
- Duff, K., Beglinger, L.J., Schoenberg, M.R., Patton, D.E., Mold, J., Scott, J.G., . . . Adams, R. (2005) Test-retest stability and practice effect of the RBANS in a community dwelling elderly sample. *Journal of Clinical and Experimental Neuropsychology*, 27, 565-75.
- Duff, K., Langebehn, D.R., Schoenberg, M.R., Moser, D.J., Baade, L.E., Mold, J., . . . Adams, R.L. (2006). Examining the Repeatable Battery for Assessment of Neuropsychological Status: Factor analytic studies in an elderly sample. *American Journal of Geriatric Psychiatry*, 14, 976-979.
- Duff, K., Patton, D., Schoenberg, M.R., Mold, J., Scott, J.G. & Adams, R.L. (2003). Age and education-correlated independent normative data for the RBANS in a community dwelling elderly sample. *The Clinical Neuropsychologist*, 17(3), 351-66.
- Duff, K., Schoenberg, M.R., Patton, D., Mold, J., Scott, J.G. & Adams, R.L. (2004). Predicting change with the RBANS in a community dwelling elderly sample. *Journal of the International Neuropsychological Society*, 10, 828-34.
- Duff, K. Schoenberg, M.R., Patton, D., Paulsen, J.S., Bayless, J.D., Mold, J., . . . Adams, R. (2005). Regression-based formulas for predicting change in RBANS subtests with older adults. *Archives of Clinical Neuropsychology*, 20, 281-90.

- Eastwood, C.A., Travis, L., Morgenstern, T.T. & Donoho, E.K. (2007). Weight and symptom diary for self-monitoring in heart failure clinic patients. *Journal of Cardiovascular Nursing*, 22(5), 382-89.
- Ekman, I., Fagerberg, B., & Skoog, I. (2001). The clinical implications of cognitive impairment in elderly patients with chronic heart failure. *Journal of Cardiovascular nursing*, 16(1), 47-55.
- Europe, E. & Tyni-Lenne, R. (2004). Qualitative analysis of the male experience of heart failure. *Heart and Lung*, 33(4), 227-34.
- Evangelista, L.S., Dracup, K. & Doering, L.V. (2000). Treatment-seeking delays in heart failure patients. *Journal of Heart and Lung Transplantation*, 19(10), 932-938.
- Fawcett, J. (2000). *Analysis and evaluation of contemporary nursing knowledge: Nursing models and theories*. Philadelphia: F.A. Davis Company.
- Field, A. (2009). *Discovering statistics using SPSS*. London: Sage Publications Ltd.
- Folstein, M.F., Folstein, S.E. & McHugh, P.R. (1975). "Mini-mental state:" A Practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189-98.
- Fratiglioni, L., Jorm, A.F., Grut, M., Viitanen, M., Holmen, K., Ahlbom, A. & Winblad, B.. (1993). Predicting dementia from the Mini-Mental State Examination in an elderly population: The role of education. *Journal of Clinical Epidemiology*, 46(3), 281-7.
- Friedman, M.M. (1997). Older adults' symptoms and their duration before hospitalization for heart failure. *Heart & Lung: The Journal of Acute and Critical Care*, 26(3), 169-76.
- Garg, R. & Yusuf, S. (1995). Overview of randomized trials of angiotensin-converting enzyme inhibitors on mortality and morbidity in patients with heart failure. *Journal of the American Medical Association*, 273, 1450-56.
- Gladsjo, J.A., Schuman, C.C., Evans, J.D., Peavy, G.M., Miller, S.W. & Heaton, R.K. (1999). Norms for letter and category fluency: Demographic corrections for age, education, and ethnicity. *Assessment*, 6(2), 147-8.
- Gold, J., Queern, C., Iannone, V.N. & Buchanan, R. (1999). Repeatable Battery for the Assessment of Neuropsychological Status as a screening test in schizophrenia, I: Sensitivity, reliability and validity. *The American Journal of Psychiatry*, 156(12), 1944-1950.

- Gontkovsky, S.T., Beatty, W.W. & Mold, J.W. (2004). Repeatable Battery for the Assessment of Neuropsychological Status in a normal geriatric sample. *Clinical Gerontologist*, 27(3), 79-86.
- Gontkovsky, S.T., Hillary, F.G. & Scott, J.G. (2002). Cross-validation and test sensitivity of the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS). *Journal of Cognitive Rehabilitation*, 20(4), 26-31.
- Gontkovsky, S.T., Mold, J.W. & Beatty, W.W. (2002). Age and educational influences on RBANS index scores in a nondemented geriatric sample. *The Clinical Neuropsychologist*, 16(3), 258-263.
- Gorkin, L., Norvell, N.K., Rosen, R.C., Charles, E., Shumaker, S.A., McIntyre, K.M. et al. (1993). Assessment of quality of life as observed from the baseline data of the studies of Left Ventricular Dysfunction (SOLVD) trial quality-of-life substudy. *The American Journal of Cardiology*, 71, 1069-73.
- Greenop, K.R., Xiao, J., Almeida, O., Flicker, L., Beer, C., Foster, J. . . Lautenschlager, N. (2010). Awareness of cognitive deficits in older adults with cognitive-impairment-no-dementia (CIND): Comparison with informant report. *Alzheimer Disease and Associated Disorders*, 25(1), 24-33.
- Grothues, F., Smith, G.C., Moon, J.C.C., Bellenger, N.G., Collins, P., Klein, H.U., & Pennell, D.J. (2002). Comparison of interstudy reproducibility of cardiovascular magnetic resonance with two dimensional echocardiography in normal subjects and in patients with heart failure or left ventricular hypertrophy. *American Journal of Cardiology*, 90, 29-34.
- Grimm, M., Yeganehfar, W., Laufer, G., Madl, C., Kramer, L., Eisenhuber, E., . . . Grimm, G. (1996). Cyclosporin may affect improvement of cognitive brain function after successful cardiac transplantation. *Circulation*, 94, 1339-45.
- Gruhn, N., Larsen, F.S., Boesgaard, S., Knudsen, G.M., Mortensen, S.A., Thomsen, G. & Aldershvile, J. (2001). Cerebral blood flow in patients with chronic heart failure before and after heart transplantation. *Stroke*, 32, 2530-33.
- Happ, M.B., Naylor, M.D. & Roe-Prior, P. (1997). Factors contributing to rehospitalization of elderly patients with heart failure. *Journal of Cardiovascular Nursing*, 11(4), 75-84.
- Hildebrand, B. (1997). Neuropsychological predictors of academic success: Use of Controlled Oral Word Association Test, Trail Making Test, and Wisconsin Card

Sorting Test as measures of academic success among community college students. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 57(8-B), 5380. (UMI No. 9701015)

Hobart, M., Goldberg, R., Bartko, J.J. & Gold, J.M. (1999). Repeatable Battery for the Assessment of Neuropsychological Status as a screening test in schizophrenia, II: Convergent/discriminant validity and diagnostic group comparisons. *The American Journal of Psychiatry*, 156(12), 1951-1957.

Horowitz, C.R., Rein, S.B. & Leventhal, H. (2004). A story of maladies, misconceptions and mishaps: Effective management of heart failure. *Social Science & Medicine*, 58, 631-43.

Hoth, K., Poppas, A., Ellison, K., Paul, R., Sokobin, A., Cho, Y. & Cohen, R. (2010). Link between change in cognition and left ventricular function following cardiac resynchronization therapy. *Journal of Cardiopulmonary Rehabilitation and Prevention*, 30, 401-08.

Hoth, K., Poppas, A., Moser, D. Paul, R. & Cohen, R. (2008). Cardiac dysfunction and cognition in older adults with heart failure. *Cognitive and Behavioral Neurology*, 21(2), 65-72.

Hou, N., Bennett, S.J., Eckert, G.J., Deer, M.M., Jennifer, E.L., Browning, S., . . . Murray, M. (2000). Correlates of mental status in heart failure [Abstract]. *Circulation*, 102(18 Supp II), II-392.

Hunt, S. A, Abraham, W.T., Chin, M.H., Feldman, A. M., Francis, G.S., Ganiats, T.G., . . . Riegel, B. (2005). ACC/AHA guideline update for the diagnosis and management of chronic heart failure in the adult-summary article: A report of the American College of Cardiology/American Heart Association task force on practice guidelines (Writing committee to update the 2001 guidelines for the evaluation and management of heart failure. *Circulation*, 112, 1825-52.

Incalzi, R.A., Trojano, L., Acanfora, D., Crisci, C., Tarantino, F., Abete, D. & Rengo, F. (2003). Verbal memory impairment in congestive heart failure. *Journal of Clinical and Experimental Neuropsychology*, 25(1), 14-23.

Iverson, G.L., Franzen, M.D. & Lovell, M.R. (1999). Normative comparisons for the Controlled Oral Word Association Test following acute traumatic brain injury. *The Clinical Neuropsychologist*, 13(4), 437-41.

Jacobson, G.A. (2005). Vulnerable research participants: Anyone may qualify. *Nursing Science Quarterly*, 18(4), 359-63.

- Jairath, N., Ulrich, C.M. & Ley, C. (2005). Ethical considerations in the recruitment of research subjects from hospitalized cardiovascular patient populations. *Journal of Cardiovascular Nursing*, 20(1), 56-61.
- James, T.D., Smith, P. & Brice, J.H. (2010). Self-reported discharge instruction adherence among different racial groups seen in the emergency department. *Journal of the National Medical Association*, 102(10), 931-936.
- Johnson, M., Maas, M. & Moorhead, S. (Eds.). (2000). *Iowa Outcomes Project Nursing Outcomes Classification (NOC)*. (2nd ed.). St. Louis: Mosby.
- Johnson-Selfridge, M.T., Zalewski, C. & Aboudarham, J. (1998). The relationship between ethnicity and word fluency. *Archives of Clinical Neuropsychology*, 13(3), 319-325.
- Kahokehr, A., Siegert, R.J. & Weatherall, M. (2004). The frequency of executive cognitive impairment in elderly rehabilitation inpatients. *Journal of Geriatric Psychiatry and Neurology*, 17(2), 68-72.
- Kalbe, E., Kessler, J., Calabrese, P., Smith, R., Passmore, A.P., Brand, M., Bullock, R. (2004). DemTect: A new, sensitive cognitive screening test to support the diagnosis of mild cognitive impairment and early dementia. *International Journal of Geriatric Psychiatry*, 19(2), 136-43
- Karlson, M.R., Edner, M., Henriksson, R., Mejnert, M., Rersson, H., Grut, M., Billing, E. (2005). A nurse based management program in heart failure affects females and persons with cognitive dysfunction most. *Patient Education and Counseling*, 58, 146-53.
- Karow, A. & Payonk, F.G. (2006). Insight and quality of life in schizophrenia: Recent findings and treatment implications. *Current Opinion in Psychiatry*, 19, 637-641.
- Katz, N. & Hartman-Maier, A. (1997). Occupational performance and metacognition. *Canadian Journal of Occupational Therapy*, 64(2), 53-62.
- Kelman, H.R., Thomas, C., Kennedy, G.J. (1994). Cognitive impairment and mortality in older community residents. *American Journal of Public Health*, 84(8), 1255-60.
- Killam, C. Cautin, R. & Santucci, A.C. (2005). Assessing the enduring residual neuropsychological effects of head trauma in college athletes who participate in contact sports. *Archives of Clinical Neuropsychology*, 20, 599-611.

- King, I. (1997). Knowledge development for nursing: A process. In I.M. King & J. Fawcett (Eds.), *The Language of nursing theory and metatheory* (pp. 9-15). Indianapolis: Center Nursing Publications.
- Kneebone, A., Andrew, M.J., Baker, R.A. & Knight, J.L. (1998). Neuropsychologic changes after coronary artery bypass grafting: Use of reliable change indices. *Annals of Thoracic Surgery*, 65, 1320-25.
- Kolb, B. & Whishaw, I. Q. (2003). *Fundamentals of human neuropsychology* (5th ed.). New York: Worth Publishers.
- Komoda, T., Drews, T., Sakurba, S., Kubo, M. & Hetzer, R. (2005). Executive cognitive dysfunction without stroke after long-term mechanical circulatory support. *ASAIO Journal*, 51(6), 764-68.
- Krumholz, H.M., Butler, J., Miller, J., Vaccarino, V., Williams, C., de Leon, C., . . . Berkman, L. (1998). Prognostic importance of emotional support for elderly patients hospitalized with heart failure. *Circulation*, 97(10), 958-64.
- Krumholz, H.M., Parent, E.M., Tu, N., Vaccarino, V., Wang, Y., Radford, M., Hennen, J. (1997). Readmission after hospitalization for congestive heart failure among Medicare beneficiaries. *Archives of Internal Medicine*, 157(1), 99-104.
- Kuhn, D. (2003). Forensic services: QEEG brain mapping and evoked responses. Retrieved August 19, 2006, from <http://www.kuhncenter.com/forensic/qeeg.shtml>.
- Larson, E.B., Kirschner, K., Bode, R., Heinemann, A. & Goodman, R. (2005). Construct and predictive validity of the Repeatable Battery for the Assessment of Neuropsychological Status in the evaluation of stroke patients. *Journal of Clinical and Experimental Neuro-psychology*, 27, 16-31.
- Launer, L.J., Dinkgreve, M., Jonker, C., Hooijer, C. & Lindeboom, J. (1993). Are age and education independent correlates of the Mini-Mental State Exam performance of community-dwelling elderly? *Journal of Gerontology*, 48(6), 271-77.
- Lezak, M.D., Howieson, D.B. & Loring, D.W. (2004). *Neuropsychological assessment* (4th ed.). Oxford: Oxford University Press.
- Lipschitz, R., Klein, G., Orasanu, J. & Salas, E. (2001). Taking stock of naturalistic decision making. *Journal of Behavioral Decision Making*, 14(5), 331-52.

- Macabasco-O'Connell, A., Crawford, M., Stotts, N., Steward, A. & Froelicher, E. (2008). Self-care behaviors in indigent patients with heart failure. *Journal of Cardiovascular Nursing*, 23(3), 223-30.
- MacIntyre, K., Capewell, S., Stewart, S., Chalmers, J.W.T., Boyd, J., Finlayson, A., . . . McMurray, J. (2000). Evidence of improving prognosis in heart failure: Trends in case fatality in 66,547 patients hospitalized between 1986 and 1995. *Circulation*, 102, 1126-31.
- MacKenzie, D.M., Copp, P., Shaw, R.J., & Goodwin, G.M. (1996). Brief cognitive screening of the elderly: A comparison of the Mini-Mental State Examination (MMSE), Abbreviated Mental Test (AMT) and Mental Status Questionnaire (MSQ). *Psychological Medicine*, 26(2), 427-30.
- Matlin, M. W. (1994). *Cognition* (3rd. ed). Fort Worth, TX: Harcourt Brace Publishers.
- McGowan, J.H. & Cleland, J.G.F. (2003). Reliability of reporting left ventricular systolic function by echocardiography: A systematic review of three methods. *American Heart Journal*, 146, 388-97.
- McGovern, T. (2007). Clinical utility of the Alzheimer's Quick Test: Comparison of the AQT, TMT, COWA, and MMSE for distinguishing mild/moderate dementia, sleep apnea and controls. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 68(5-B), 3403. (UMI No. 3268433).
- McKay, C., Casey, J.E., Wertheimer, J. & Fichtenberg, N.L. (2007). Reliability and validity of the RBANS in a traumatic brain injured sample. *Archives of Clinical Neuropsychology*, 22, 91-98.
- MERIT-HF Study Group. (1999). Effect of metoprolol CR/XL in chronic heart failure: Metoprolol CR/XL randomized intervention trial in congestive heart failure (MERIT-HF). *Lancet*, 353, 2001-9.
- Mezey, M., Teresi, J., Ramsey, G., Mitty, E. & Bobrowitz, T. (2000). Decision-making capacity to execute a health care proxy: Development and testing of guidelines. *Journal of the American Geriatrics Society*, 48(2), 179-87.
- Migliorelli, R., Teson, A., Sabe, L., Petracca, G., Petracchi, M., Leiguarda, R., . . . Starkstein, S.E. (1995). Anosognosia in Alzheimer's Disease: A study of associated factors. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 7, 338-44.

- Morris, W. (Ed.). (1980). *The new American heritage dictionary of the English language*. Boston: Houghton Mifflin Company.
- Murberg, T.A. & Bru, E. (2001). Social relationships and mortality in patients with congestive heart failure. *Journal of Psychosomatic Research*, 51, 521-27.
- Nardi, R., Fiorino, S. Borioni, D., Agostini, D., D'Anastasio, C., Marchetti, C., Muratori, M. (2007). Comprehensive complexity assessment as a key tool for the prediction of in-hospital mortality in heart failure or aged patients admitted to internal medicine wards. *Archives of Gerontology and Geriatrics*, 44(Supp 1), 279-88.
- National Heart, Lung and Blood Institute. (September, 2006). Fact book, fiscal year 2006, from <http://www.nhlbi.nih.gov/about/05factbk.pdf>.
- National Heart, Lung and Blood Institute. (September, 1996). Congestive heart failure in the United States: A new epidemic. Retrieved April 6, 2004 from <http://nhlbi.nih.gov/health/public/heart/other/CHF.htm>.
- Ni, H. Nauman, D., Burgess, D., Wise, K., Crispell, K. & Hershberger, R.E. (1999). Factors influencing knowledge of and adherence to self-care among patients with heart failure. *Archives of Internal Medicine*, 159, 1613-1619.
- Nunnally, J.C. & Bernstein, I.H. (1994). *Psychometric theory* (3rd. Ed.). USA: McGraw-Hill, Inc.
- O'Connell, J.B. (2000). The economic burden of heart failure. *Clinical Cardiology*, 23(Supp III), III-6-III-10.
- Okonkwo, O., Cohen, R., Gunstad, J., Tremont, G., Alosco, M. & Poppas, A. (2010). Longitudinal trajectories of cognitive decline among older adults with cardiovascular disease. *Cerebrovascular Disorders*, 30, 362-73.
- Okonkwo, O., Griffith, H., Vance, D., Marson, D., Ball, K. & Wadley, V. (2009). Awareness of functional difficulties in mild cognitive impairment: A multidomain assessment approach. *Journal of the American Geriatrics Society*, 57, 978-84.
- Okonkwo, O., Wadley, V., Griffith, H., Belue, K., Lanza, S., Zamrini, E., . . . Marson, D. (2008). Awareness of deficits in financial abilities in patients with mild cognitive impairment: Going beyond self-informant discrepancy. *American Association for Geriatric Psychiatry*, 16, 650-59.

- Olin, J.T. & Zelinski, E.M. (1991). The 12 month reliability of the Mini-Mental State Examination. *Psychological Assessment: A Journal of Consulting and Clinical Psychology*, 3(3), 427-32.
- Orfei, M., Varsi, A., Blundo, C., Celia, E., Casini, A., Caltagirone, C. & Spalletta, G. (2010). Anosognosia in mild cognitive impairment and mild Alzheimer's Disease: Frequency and neuropsychological correlates. *American Journal of Geriatric Psychiatry*, 18, 1133-40.
- Pachet, A.K. (2007). Construct validity of the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) with acquired brain injury. *The Clinical Neuropsychologist*, 21, 286-93.
- Packer, M, Coats, A.J.S., Fowler, M.B., Katus, H.A., Krum, H., Mohacsi, P. Rouleau, J.L., . . . DeMets, D.L. (2001). Effect of carvedilol on survival in severe chronic heart failure. *New England Journal of Medicine*, 344, 1651-58.
- Pahor, M., Manto, A., Pedone, C., Carosella, L., Guralnik, J.M. & Carbonin, P. (1996). Age and severe drug reactions caused by nifedipine and verapamil. *Journal of Clinical Epidemiology*, 49(8), 921-28.
- Paradis, V., Cossette, S., Frasure-Smith, N., Heppell, S. & Guertin, M. (2010). The efficacy of a motivational nursing intervention based on the stages of change on self-care in heart failure patients. *Journal of Cardiovascular Nursing*, 25(2), 130-141.
- Patton, D.E., Duff, K., Schoenberg, M.R., Mold, J., Scott, J.G. & Adams, R.L. (2003). Performance of cognitively normal African-Americans on the RBANS in community dwelling older adults. *The Clinical Neuropsychologist*, 17(4), 515-30.
- Patton, D.E., Duff, K., Schoenberg, M.R., Mold, J., Scott, J.G. & Adams, R.L. (2005). Base rates of longitudinal RBANS discrepancies at one and two year intervals in community-dwelling older adults. *The Clinical Neuropsychologist*, 19(1), 27-44.
- Patton, D.E., Duff, K., Schoenberg, M.R., Mold, J., Scott, J.G. & Adams, R.L. (2006). RBANS index discrepancies: Base rates for older adults. *Archives of Clinical Neuropsychology*, 21, 151-60.
- Perret, E. (1974). The left frontal lobe of man and the suppression of habitual responses in verbal categorical behaviour. *Neuropsychologia*, 12, 323-30.

- Petrucci, R.J., Truesdell, K.C., Carter, A., Goldstein, N.E., Russell, M.M., Dilkes, D. et al. (2006). Cognitive dysfunction in advanced heart failure and prospective cardiac assist device patients. *Annals of Thoracic Surgery*, 81, 1738-44.
- Pineda, D.A. & Merchan, V. (2003). Executive function in young Colombian adults. *International Journal of Neuroscience*, 113, 397-410.
- Powell, L.H., Calvin, J.E., Richardson, D., Janssen, I., Mendes de Leon, C.F., . . . Avery, E. (2010). Self-management counseling in patients with heart failure: The heart failure adherence and retention randomized behavioral trial. *Journal of the American Medical Association*, 304(12), 1331-1338. Retrieved from <http://www.jama.ama-assn.org>, April 1, 2011.
- Pressler, S., Subramanian, U., Kareken, D., Perkins, S., Gradus-Pizlo, I., Sauve, M., . . . Shaw, R. (2010). Cognitive deficits in chronic heart failure. *Nursing Research*, 59(2), 127-39.
- Putzke, J.D., Williams, M.A., Daniel, F.J., Foley, B.A., Kirklin, J.K., & Boll, T.J. (2000). Neuropsychological functioning among heart transplant candidates: A case control study. *Journal of Clinical and Experimental Neuropsychology*, 22(1), 95-103.
- Putzke, J.D., Williams, M.A., Millsaps, C.L., Azrin, R.L., LaMarche, J.A., Bourge, . . . Boll, T. (1997). Heart transplant candidates: A neuropsychological descriptive database. *Journal of Clinical Psychology in Medical Settings*, 4(3), 343-55.
- Quinn, C., Dunbar, S. & Higgins, M. (2010). Heart failure symptom assessment and management: Can caregivers serve as proxy? *Journal of Cardiovascular Nursing*, 25(2), 142-48.
- Randolph, C. (1998). *Repeatable Battery for the Assessment of Neuropsychological Status Manual*. San Antonio, TX: The Psychological Corporation.
- Randolph, C., Tierney, M.C., Mohr, E. and Chase, T.N. (1998). The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS): Preliminary clinical validity. *Journal of Clinical and Experimental Neuropsychology*, 20(3), 310-19.
- Riegel, B., Bennett, J.A., Davis, A., Carlson, B., Montague, K. Robin, H. & Glaser, D. (2002). Cognitive impairment in heart failure: Issues of measurement and etiology. *American Journal of Critical Care*, 11(6), 520-28.
- Riegel, B. & Carlson, B. (2002). Facilitators and barriers to heart failure self care. *Patient Education and Counseling*, 46, 287-95.

- Riegel, B. & Carlson, B. (2004). Is individual peer support a promising intervention for persons with heart failure? *Journal of Cardiovascular Nursing*, 19(3), 174-83.
- Riegel, B., Carlson, B. & Glaser, D. (2000). Development and testing of a clinical tool measuring self management of heart failure. *Heart & Lung*, 29(1), 4-14.
- Riegel, B., Carlson, B., Moser, D.K., Sebern, M., Hicks, F.D. & Roland, V. (2004). Psychometric testing of the Self-Care of Heart Failure Index. *Journal of Cardiac Failure*, 10(4), 350-360.
- Riegel, B., Dickson, V.V., Goldberg, L.R. & Deatricks, J.A. (2007). Factors associated with the development of expertise in heart failure self-care. *Nursing Research*, 56(4), 235-43.
- Riegel, B., Dickson, V.V., Hoke, L., McMahon, J.P., Reis, B.F. & Sayers, S. (2006). A motivational counseling approach to improving heart failure self care: Mechanisms of effectiveness. *Journal of Cardiovascular Nursing*, 21(3), 232-41.
- Riegel, B., Lee, C., Dickson, V. & Carlson, B. (2009). An update on the Self-Care in Heart Failure Index. *Journal of Cardiovascular Nursing*, 24(6), 485-97.
- Rockwell, J.M. & Riegel, B. (2001). Predictors of self care in persons with heart failure. *Heart & Lung*, 30(1), 18-25.
- Roger, V., Go, A., Lloyd-Jones, D., Adams, R., Berry, J., Brown, T., . . . Wylie-Rosett, J. (2011). Heart disease and stroke statistics 2011 update: A report from the American Heart Association. *Circulation*, 123, e18-e209. Doi: 10.1161/CIR.0b013e3182009701
- Rogers, A.E., Addington-Hall, J.M., McCoy, A.S.M., Edmonds, P.M., Abern, A.J., Coats, A.J.S. & Gibbs, J.S. (2002). A qualitative study of chronic heart failure patients' understanding of their symptoms and drug therapy. *The European Journal of Heart Failure*, 4, 283-87.
- Ross, T.P., Calhoun, E., Cox, T., Wenner, C., Kono, W. & Pleasant, M. (2007). The reliability and validity of qualitative scores for the Controlled Oral Word Association Test. *Archives of Clinical Neuropsychology*, 22, 475-88.
- Rossi, A., Daneluzzo, E., Mattei, P., Bustini, M., Casacchia, M. & Stratta, P. (1997). Wisconsin card sorting test and stroop test performances in Schizophrenia: a shared construct. *Neuroscience Letters*, 226(2), 87-90.

- Roy, C. & Andrews, H.A. (1999). *The Roy adaptation model* (2nd ed.). Stamford, CT: Appleton & Lange.
- Ruff, R.M., Light, R.H., Parker, S.B. & Levin, H.S. (1996). Benton Controlled Oral Word Association Test: Reliability and updated norms. *Archives of Clinical Neuropsychology*, 11(4), 329-38.
- Ruff, R.M., Light, R.H., Parker, S.B. & Levin, H.S. (1997). The psychological construct of word fluency. *Brain and Language*, 57, 394-405.
- Ryder, K.A., McSwan, K.L., Scott, J.G., Bharucha, K.J. & Beatty, W.W. (2002). Cognitive function in Parkinson's disease: Association with anxiety but not depression. *Aging Neuropsychology and Cognition*, 9(2), 77-84.
- Sabatini, T., Barbisoni, P., Rozzini, R., & Trabucchi, M. (2002). Hypotension and cognitive impairment: Selective association in patients with heart failure. *Neurology*, 59(4), 651.
- Sauve, M.J., & Bennett, S.J. (1999). Unrecognized cognitive deficits in chronic heart failure: The pilot [Abstract]. *Circulation*, 100 (18 supp I), I-253.
- Sauve, M.J. & Bennett, S.J. (2000). Cognitive impairments, depression and medication compliance in patients with chronic heart failure [Abstract]. *Circulation*, 102(18 supp II), II-392.
- Schall, R.R., Petrucci, R.J., Brozena, S.C., Cavarocchi, N.C., & Jessup, M. (1989). Cognitive function in patients with symptomatic dilated cardiomyopathy before and after cardiac transplantation. *Journal of the American College of Cardiology*, 14(7), 1666-71.
- Schnell-Hoehn, K., Naimark, B. & Tate, R. (2009). Determinants of self-care behaviors in community dwelling patients with heart failure. *Journal of Cardiovascular Nursing*, 24(1), 40-47.
- Schwarz, K.A. & Elman, C.S. (2003). Identification of factors predictive of hospital readmissions for patients with heart failure. *Heart & Lung*, 32(2), 88-99.
- Schweitzer, R.D., Head, K. & Dwyer, J.W. (2007). Psychological factors and treatment adherence behavior in patients with chronic heart failure. *Journal of Cardiovascular Nursing*, 22(1), 76-83.

- Seto, E., Leoard, K., Cafazzo, J., Masino, C., Barnsley, J. & Ross, H. (2011). Self-care and quality of life of heart failure patients at a multidisciplinary heart function clinic. *Journal of Cardiovascular Nursing*. Advance on line publication. doi: 10.1097/JCN.0b013e31820612b8
- Shultz, K.S. & Whitney, D.J. (2005). *Measurement theory in action: Case studies and exercises*. Thousand Oaks, CA: Sage Publications.
- Sloan, R.S. & Pressler, S.J. (2009). Cognitive deficits in heart failure: Re-cognition of vulnerability as a strange new world. *Journal of Cardiovascular Nursing*, 24(3), 241-8.
- Spren, O. & Straus, E. (1998). *A compendium of neuropsychological tests* (2nd ed.). New York: Oxford University Press.
- Stanek, K.M., Gunstad, J., Paul, R.H., Poppas, A., Jefferson, A.L., Sweet, L.H., . . . Cohen, R.A. (2009). Longitudinal cognitive performance in older adults with cardiovascular disease: Evidence for improvement in heart failure. *Journal of Cardiovascular Nursing*, 24(3), 192-97.
- Starkstein, S., Jorge, R., Mizrahi, R., Adrian, J. & Robinson, R.G. (2007). Insight and danger in Alzheimer's disease. *European Journal of Neurology*, 14, 455-60.
- Starkstein, S., Jorge, R., Mizrahi, R. & Robinson, R.G. (2006). A diagnostic formulation for anosognosia in Alzheimer's disease. *Journal of Neurology, Neurosurgery & Psychiatry*, 77(6), 719-25.
- Starkstein, S., Sabe, L., Cuerva, A.G., Kuzis, G., Leiguarda, R. (1997). Anosognosia and procedural learning in Alzheimer's disease. *Neuropsychiatry, Neuropsychology and Behavioral Neurology*, 10(2), 96-101.
- Starkstein, S., Vazquez, S., Migliorelli, R., Teson, A., Sabe, L. & Leiguarda, R. (1995). A single-photon emission computed tomographic study of anosognosia in Alzheimer's Disease. *Archives of Neurology*, 52(4), 415-20.
- StatSoft, Inc. (1984-2003). *Multiple regression*. Retrieved August 31, 2007, from <http://www.statsoft.com/textbook/stathome.html>.
- Steinke, E.E. (2004). Research ethics, informed consent and participant recruitment. *Clinical Nurse Specialist*, 18(2), 88-95.
- Stump, T.E., Callahan, C.M. & Hendrie, H.C. (2001). Cognitive impairment and mortality in older primary care patients. *Journal of the American Geriatrics Society*, 49, 934-40.

- Sumerall, S.W., Timmons, P.L., James, A.L., Ewing, M.J.M. & Oehlert, M.E. (1997). Expanded norms for the Controlled Oral Word Association Test. *Journal of Clinical Psychology*, 53(5), 517-21.
- Sutton, L.B., Erlen, J.A., Glad, J.M. & Siminoff, L.A. (2003). Recruiting vulnerable populations for research: Revisiting the ethical issues. *Journal of Professional Nursing*, 19(2), 106-112.
- Tabachnick, B.G. & Fidell, L.S. (1996). *Using multivariate statistics* (3rd ed.). New York: HarperCollins.
- Tangalos, E.G., Smith, G.E., Ivnik, R.J., Petersen, R.C., Kokmen, E., Kurland, L.T., . . . Parisi, J. (1996). The Mini-Mental State Examination in general medical practice: Clinical utility and acceptance. *Mayo Clinic Proceedings*, 71(9), 829-37.
- Thomas, S.B., Sansing, V.V., Davis, A., Magee, M., Massaro, E., Srinivas, V.S., . . . Brooks, M. M. (2010). Racial differences in the association between self-rated health status and objective clinical measures among participants I the BARI 2D trial. *American Journal of Public Health*, 100(S1), S269-276. doi: 10.2105/AJPH.2009.176180
- Tombaugh, T.N., Kozak, J. & Rees, L. (1999). Normative data stratified by age and education for two measures of verbal fluency: FAS and animal naming. *Archives of Clinical Neuropsychology*, 14(2), 167-77.
- Tombaugh, T.N. & McIntyre, N.J. (1992). The Mini-Mental State Examination: A comprehensive review. *Progress in Geriatrics*, 40, 922-35.
- Trojano, L., Incalzi, R.A., Acanfora, D., Picone, C., Mecocci, P., & Rengo, F. (2003). Cognitive impairment: A key feature of congestive heart failure in the elderly. *Journal of Neurology*, 250, 1456-63.
- Tzourio, C., Anderson, C., Chapman, N., Woodward, M., Neal, B., MacMahon, S. & Chalmers, J. (2003). Effects of blood pressure lowering with perindopril and indapamide therapy on dementia and cognitive decline in patients with cerebrovascular disease. *Archives of Internal Medicine*, 163(9), 1069-75.
- U.S. Department of Health and Human Services, National Institutes of Health, (2009). Monitoring adherence to the NIH policy on the inclusion of women and minorities as subjects in clinical research. Retrieved from <http://owrh.od.nih.gov/inclusion/2009/AnnualTrackingInclusionComprehensiveRpt/pdf>.

- Vogel, A., Hasselbalch, S.G., Gade, A., Ziebell, M. & Waldemar, G. (2005). Cognitive and functional neuroimaging correlates for anosognosia in mild cognitive impairment and Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 20, 238-246.
- Wilde, M.C. (2006). The validity of the Repeatable Battery for the Assessment of Neuropsychological Status in acute stroke. *The Clinical Neuropsychologist*, 20-702-15.
- Wilk, C.M., Gold, J.M., Bartko, J.J., Dickerson, F., Fenton, W.S., Knable, M., . . . Buchanan, R.W. (2002). Test-retest stability of the Repeatable Battery for the Assessment of Neuropsychological Status in schizophrenia. *American Journal of Psychiatry*, 159, 838-44.
- Wilk, C., Gold, J.M., Humber, K., Dickerson, F., Fenton, W.C. & Buchanan, R.W. (2003). Brief cognitive assessment in schizophrenia: Normative data for the Repeatable Battery for the Assessment of Neuropsychological Status. *Schizophrenia Research*, 70, 175-86.
- Wilson, L.A. & Brass, W. (1973). Brief assessment of the mental state in geriatric domiciliary practice: The usefulness of the Mental Status Questionnaire. *Age and Aging*, 2, 92-101.
- Wolfe, R., Worrall-Carter, L., Foister, K., Keks, N. & Howe, V. (2006). Assessment of cognitive function in heart failure patients. *European Journal of Cardiovascular Nursing*, 5, 158-64.
- Wood, M.J. & Brink, P.J. (1998). Correlational designs. In P.J. Brink & M.J. Wood (Eds.), *Advanced design in nursing research* (2nd Ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Wu, J., Lennie, T., DeJong, M., Frazier, S., Heo, S., Chung, M. & Moser, D. (2010). Medication adherence is a mediator of the relationship between ethnicity and event free survival in patients with heart failure. *Journal of Cardiac Failure*, 16(2), 142-149.
- Yancy, C.W., Lopatin, M., Stevenson, L., DeMarco, T. & Fonarow, G. (2006). Clinical presentation, management, and in-hospital outcomes of patients admitted with acute decompensated heart failure with preserved systolic function. *Journal of the American College of Cardiology*, 47(1), 76-84.

- Yehle, K.S., Hess, A.M., Plake, K.S., Murawski, M.M. & Mason, H.L. (2010). Health literacy and self-care of patients with heart failure [Abstract]. *Heart & Lung*, 39(4), 351.
- Yehle, K.S., Sands, L.P., Rhynders, P.A. & Newton, G.D. (2009). The effect of shared medical visits on knowledge and self-care in patients with heart failure: A pilot study. *Heart & Lung*, 38(1), 25-33.
- Yeudall, L.T., Fromm, D., Reddon, J.R., Stefanyk, W.O. (1986). Normative data stratified by age and sex for 12 neuropsychological tests. *Journal of Clinical Psychology*, 42(6), 918-946.
- Zambroski, C.H. (2003). Qualitative analysis of living with heart failure. *Heart & Lung*, 23(1), 32-40.
- Zuccala, G., Cattell, C., Manes-Gravina, E., Di Niro, M.G., Cocchi, A., & Bernabei, R. (1997). Left ventricular dysfunction: A clue to cognitive impairment in older patients with heart failure. *Journal of Neurology, Neurosurgery and Psychiatry*, 63, 509-12.
- Zuccala, G., Marzetti, E., Cesari, M., LoMonaco, M.R., Antonica, L., Cocchi, A., . . . Bernabei, R. (2005). Correlates of cognitive impairment among patients with heart failure: Results of a multicenter survey. *The American Journal of Medicine*, 118, 496-502.
- Zuccala, G., Onder, G., Marzetti, E., LoMonaco, M.R., Cesari, M., Cocchi, A., . . . Bernabei, R. (2005). Use of angiotensin-converting enzyme inhibitors and variations in cognitive performance among patients with heart failure. *European Heart Journal*, 26, 226-33.
- Zuccala, G., Onder, G., Pedone, C., Carosella, L., Pahor, M., Bernabei, R. & Cocchi, A. (2001). Hypotension and cognitive impairment: Selective association in patients with heart failure. *Neurology*, 57, 1986-92.
- Zuccala, G., Onder, G., Pedone, C., Cocchi, A., Carosella, L., Cattell, C., . . . Bernabei, R. (2001). Cognitive dysfunction as a major determinant of disability in patients with heart failure: Results from a multicentre survey. *Journal of Neurology, Neurosurgery and Psychiatry*, 70(1), 109-112.
- Zuccala, G., Pedone, C., Cesari, M., Onder, G., Pahor, M., Marzetti, E., . . . Bernabei, R. (2003). The effects of cognitive impairment on mortality among hospitalized patients with heart failure. *The American Journal of Medicine*, 115, 97-103.

VITA

Catherine Murks is a licensed advance practice nurse. She received an Associate of Science degree in Nursing from Purdue University Calumet Campus. She then received a Bachelor of Science degree in Nursing from Purdue University Calumet Campus (Nurse Practitioner), followed by a Master of Science degree from Purdue University Calumet (Clinical Nurse Specialist). She worked as a critical care nurse in a large urban community hospital for many years, earning certification as a Critical Care Nurse (CCRN). She advanced her career at the University of Chicago Medical Center, where she was first a Clinical Nurse Specialist in Cardiac Surgery, and later a Nurse Practitioner in the Center for Heart Failure Management, where she remains to this date. As a nurse practitioner, Catherine is responsible for managing a caseload of patients who are waiting for or who have received, a cardiac transplant. In this position, she was instrumental in the growth of the program to one of the largest cardiac transplant programs in the state of Illinois. She was also responsible for developing the ventricular assist device program and co-authored the application document for Medicare approval for the cardiac transplant program. While she was the Clinical Nurse Specialist for cardiac surgery, Catherine was co-investigator on a study evaluating skin breakdown in cardiac surgical patients. Catherine returned to school to advance her education at Loyola University in Chicago, to a Doctorate in Philosophy in the discipline of nursing.